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A PRISON WITHIN A PRISON

SEGREGATION OF HIV POSITIVE INMATES AND DOUBLE STIGMA

by

**EMILY HILYER GASKIN** 

Under the Direction of Cassandra White

**ABSTRACT** 

Although the majority of state prison systems have made the move away from segregated housing for HIV positive inmates, a few still continue this practice. The purpose of this study was to learn more about the experiences of women who have carried the double stigma of being HIV positive prisoners who were segregated within the prison system because of their illness. Drawing on interviews with HIV positive women who served time in a segregated facility and are now released, I was able to explore how double stigma and segregation affect identity and daily life. By asking these women questions about their experiences as inmates who were further segregated because of their HIV status, I call attention to the strong association between power,

INDEX WORDS: Medical anthropology, HIV/AIDS, Prisons, Women, Segregation, Stigma, Power, Knowledge, Feminism

authoritative knowledge, and policy.

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by

# EMILY HILYER GASKIN

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

In the College of Arts and Sciences

Georgia State University

2009

# A PRISON WITHIN A PRISON SEGREGATION OF HIV POSITIVE INMATES AND DOUBLE STIGMA

by

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# DEDICATION

Over the course of this research I have been fortunate enough to meet an inspiring group of women. These women are thoughtful, empowered, and incredibly generous in terms of helping me with my work. This work is in honor of those women and the spirit of what they began in that prison in 1987. I am incredibly humbled and grateful to have met and shared with them.

#### **ACKNOWLEDGEMENTS**

First and foremost I would like to acknowledge my advisor Dr. Cassandra White, whose patience and positivity were incredibly helpful in the writing of this document. Also, thanks to my other committee members, Dr. Emanuela Guano and Dr. Susan McCombie for their support and guidance. I would also like to thank those organizations with whom I worked, including the ACLU. Particular thanks go to Jackie Walker, of the ACLU's National Prison Project, AIDS Inmate Mothers, and the Southern Center for Human Rights. I greatly appreciate the help I received from other scholars working with prisoner's rights who endured question after question from me via email: Lorna Rhodes, Benjamin Fleury-Steiner, and Brackett Williams. Thanks to Bryan Terwilliger for putting up with countless meltdowns. Of course, I have to thank Carla, Juliette, Marilyn, and Tasha who are my inspiration and friends.

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#### INTRODUCTION

My interest in the stigma associated with HIV/AIDS began early in my life although I could not fully comprehend its depth at the time. I knew that people around me expressed fear and shame in knowing a friend of the family who had died from AIDS. I also internalized this shame that was felt by the adults in my life without really understanding why. At my school, parents began to worry that their children could be infected at school. Rumors circulated about catching it at the movie theater or from a pay phone. Homosexuals, drug users, and minorities became the "face" of the disease even if they were completely healthy. Robinette and Long describe the problems that the stigma of AIDS has had: "From its outbreak in the United States..... AIDS has created fear, not simply as a lethal disease but also by the contact through which the disease was contracted" (1999: 105). At that time, panic had completely clouded society's ability to think rationally.

As I grew older I began to ask myself why fatal diseases associated with some moral choice were stigmatized far worse than those that were not. In other words, what does society say about a person who has HIV/AIDS versus a person who has heart disease? Why does our treatment of individuals with HIV/AIDS involve so much more exclusion? Perhaps, in a morally conservative society, those diseases linked with homosexuality or drug use become deviant and dangerous by association. This dialogue also contains within it a somewhat racist connotation, which is visible in media images, and provides justification for portraying minorities as stereotypically "dangerous" and deserving of control.

When I began to unpack the many layers of social stigma surrounding HIV/AIDS I found that this disease has simply replaced older stigmatized medical conditions such as Hansen's disease or syphilis in the social psyche. A pattern begins to emerge that links those in power, for

example the state, with the dominant discourse in society. This correlation between power and knowledge goes a long way toward determining what a society deems "dangerous" and is continually bound up within economic and political currents. The stigma surrounding HIV/AIDS is another example of this principle at work in our society.

In my second semester of graduate school, I began working with HIV positive inmates. I was a research assistant to a public health project evaluating the pre-release program for HIV positive inmates in the state of Georgia. This was my introduction into the highly controversial management of the ever growing HIV positive prison population and the enormous prison population, in general, in the United States. I could see how both prisoners and prison staff struggled with the contradictions they encountered in the everyday routine of the prison. They had to cope with a growing prison population, a small budget, and the sometimes confusing prison classification system. Behind the locked gates of the prison I found there was so much more being represented there than just its function as "a place where criminals are kept". I found that even the words "criminal", "dangerous", and "rational" were all relative.

For me, the modern prison still echoed the historical prison as it was conceived by Jeremy Bentham's panopticon and interpreted by Michel Foucault in *Discipline and Punish* (1975). Bentham rationalized that the gaze directed at an individual inmate's body worked to rehabilitate him by forcing him to internalize that gaze and become disciplined because of it. This also carries with it the implication of the duality of reason and rationality (the prison) versus madness and danger (the inmates). In her book *Total Confinement* (2004), Lorna Rhodes questions the rationality of the prison and argues that it may sometimes work in the reverse. In other words, are we really letting loose into society people that have become disciplined and docile? What then, does it mean to be a social being?

During my work on the prison project, I was made aware of the policy of segregation in the prison of HIV positive inmates. My first reaction was that this seemed understandable due to the large percentage of HIV positive incarcerated individuals. I was surprised at how fiercely one of the women in the project was against it. I remember her saying that segregation would never happen in Georgia because it was an obvious violation of human rights. When I began to speak with those involved with the prison system I discovered that no one sat in the middle. You were for it or against it and both sides could offer up countless reasons for their choice. The issue was one with which most in the prison system were familiar. Those not familiar with the prison system mirrored my reaction. It seemed as if we had all forgotten that there are many different types of people living with HIV/AIDS and we had once again defaulted to a stereotypical image that existed in society.

In the documentary, *Bus 174* (2002), Brazilian political scientist Luiz Eduardo Soares says we render people as socially invisible in two ways: we neglect them or we cast a stigma over them. In the latter we find a way to sweep these people under the rug and to "disappear" the problem through total isolation so that we need not deal with a larger issue. Once I realized this, I understood why the woman with whom I worked had such an intense reaction. I wondered how the inmates themselves internalized this treatment and this stigma. How did this factor into the construction of their identity? What were their reactions?

#### Separate but Not Equal

In 1984, the first court case on the issue of segregation of HIV positive prisoners was heard in the state of New York. These inmates argued that they were being discriminated against based on their HIV status and did not receive "identical treatment" compared to inmates in the regular prison population. In many of the segregated facilities, infected inmates were denied

access to recreation, vocational schooling, counseling programs, and medical care (Clements, 1989; Robinette and Long, 1999; Zaitzow, 2001). Some of these inmates were also kept in segregated housing, either in a separate building or a separate area, apart from the general population. Even prisoners who were otherwise healthy or were serving shorter sentences were deprived access to these programs and were segregated. The opinion of the court in the 1984 case was that they were not discriminated against because they "were not seen as similarly situated to other prisoners and therefore had no right to equal treatment" (Olivero and Roberts, 1989:7). According to this rationale, HIV status was held as an equivalent to other forms of prisoner classification such as those convicted of violent or sexual crimes or those with mental health issues. Throughout much of the 1980s cases of this nature were brought to court with startlingly consistent rulings against the inmates.

Many of these measures were based on panic and fear that, in many ways, mirrored society's general perceptions about the spread of AIDS at the time. This fear created a stigma that needed to be placed on a certain group of people by identifying them as "dangerous".

Because AIDS was predominantly found in homosexual men, IV drug users, and African Americans, these people became the symbol and source of society's stigma. Another scapegoat for AIDS infection was Haitians. Paul Farmer discusses similar public bias in his 2005 book, *Pathologies of Power*: "The persistent notion of Haitians as infected and, more important, *infecting*, underpinned much of the American response [to immigration issues]" (66) and therefore detainment and segregation of an entire population. By identifying a particular group as "dangerous", society finds something tangible to project its fears onto. This group can then be systematically cast out as deviant and therefore deserving of control.

During the 1980s, many publications, both popular and scholarly, described the rising percentages of HIV infection in the prison and the subsequent infection of African American women by former male inmates. In Sloop's 1996 book, he discusses conceptions society has of the common criminal. He notes that media images call to mind the face of an African American under thirty-five behind the bars of a prison cell which is what we see in prison demographics with 900,000 of the 2.2 million people behind bars being African American (Mauer and King, 2007). Perhaps, because of this association between rates of incarceration and HIV status, prisons have been called "the most potentially dangerous incubators of the HIV/AIDS epidemic in the United States" (Bryan, Robbins, Ruiz, O'Neill, 2006:154). In this narrative, state prison systems find the justification they need to segregate those who are HIV positive and hold a medical condition as priority over all other aspects of a prisoner's history.

The segregation policies were based on a number of justifications: 1. to prevent further infection; 2. to protect infected inmates from violence; 3. to limit exposures to opportunistic infections; 4. to protect prison staff. In recent years segregation has fallen out of favor as a sensible solution and the justifications for isolation have been disproved. In 1989, eight states evaluated each HIV positive individual to determine their classification and six states completely segregated and denied access to programs (Clements, 1989). In 2008, only three states – Alabama, South Carolina, and Mississippi - continue to use some form of segregation based on HIV status and are in legal battles with inmates in regards to restricted access.

#### Women in Prison

Female inmates present an even more interesting case for segregation within the prison system. The majority of women in the prison system are women of color and statistics show these women are disproportionately affected by HIV/AIDS. Based on this, the incidence of HIV

infection of female inmates has continued to rise since the late 1990s. Although women represent a higher prevalence of HIV infection within the prison, there are still fewer women actually being imprisoned than men which leads to a much smaller budget for women's prisons. Women commonly need more medical attention than do men both physically and emotionally. In her 2001 study of female inmates, Zaitzow argues that reproductive issues, histories of abuse, and separation from family and children affect women more powerfully than men. Female inmates also highlight the larger issue of gender roles within our society. L. Mara Dodge describes the limited scope through which we view a woman's "femininity"; female inmates have been historically seen as more troublesome because they run contradictory to a societal image of a female (1999: 925). In addition, women infected with HIV take on the stigma associated with sexual promiscuity. Parker and Aggleton found that in relation to HIV-related stigma and discrimination, women who are HIV positive are often identified as "sex workers" and therefore "vectors" for the spread of the disease (2002: 7). These layers of identity make the study of the HIV positive female inmate a particularly unique case.

# The Prison Industrial Complex

Today, the U.S. houses more of its citizens behind bars than any other country in the world with the U.S. rate of incarceration topping out in 1999 at 762 per 100,000 people (Bureau of Justice Statistics, 2008). Of the 2.2 million people said to be serving time, 40% are classified as African American and 20% as Hispanic (Mauer and King, 2007: 1). Non-violent crimes such as drug and property offenses make up 82% of the sentences being served (Bureau of Justice Staistics, 1999) and America's War on Drugs has created a revolving door through which marginalized populations cycle in and out of the system.

The Prison Industrial Complex came as a result of globalization and jobs being taken from Americans as companies looked for cheaper labor overseas. This loss was most deeply felt in urban areas where minority groups were forced into poverty which resulted in drug addiction, desperation, and crime. Instead of dealing directly with the issue of job loss and an increased dependence on government welfare, government officials launched "wars on crime and drugs" in order to criminalize these groups of people (Sudbury, 2005: 166). The emergence of the relationship between private corporations and the prison systems has allowed for public money to be spent on building more prisons, to fill with more people, and perpetuate racist policies against groups. This growth in prisons leads to jobs for those in rural areas in which prisons are built, cheap labor for corporations, and an increased census for smaller towns (Rhodes, 2004: 10).

By criminalizing certain groups of people, we make the environment ripe for policies that render groups socially invisible. These practices of confinement can be highly problematic because they symbolize a deeper agenda that plays out through the rationale of social isolation as the way to protect from social danger. In a capitalist society, a person's value is measured by their productivity and when an inmate is stripped of the ability to be useful, society views them as useless. Holding large groups of people behind bars not only frees up jobs on the outside but it also creates a space to detain marginalized and economically vulnerable populations in an endless succession of conviction and release. After one's body is rendered useless it can be very difficult for that person to ever escape the system. Women are especially vulnerable within this system because they often are caretakers for children and older relatives. Their productivity is measured by how well they can provide as the base of the family. With a lack of upward mobility and in order to survive, some women resort to crime.

# Thinking about Confinement

The idea of incarceration and segregation of "dangerous" people is one that is pervasive throughout history and serves as a justification for policy and institution building as an instrument of control. When dealing with the issue of segregation of HIV positive inmates there are a few things to consider in relation to this idea of control. First, how does identity construction figure in and what happens to agency in this context? Second, accounting for individual agency, how well does the prison system really function as an instrument of control? In the chapters that follow, I will try to lay out how the women in my study experienced this system and what their reactions were to it. The following chapter will deal with relevant literature related to control of "dangerous" people and the many different ways we can talk about it. The next two chapters focus on methodology, ethics, and my research methods. Chapter Four looks at stigma and how the women accept and integrate knowledge of their HIV positive status and segregation. Chapter Five looks at the power dynamics at work within the prison and the social relationships between the staff and the inmates. It examines how the idea of "choice" is used to create a false sense of agency and how the women view this in terms of an institution they regard as irrational. Chapter Six explores the concept of agency further and looks at reactions against segregation and the ways in which the women have empowered themselves. Chapter Seven explores the unique situation of HIV positive women in prison and how they deal with issues related to family, medicine, and the prison as a patriarchal system. Finally, I offer my insight into my findings by arguing that the quality of prison reform must be reframed and couched in the context of the women themselves.

### 1. LITERATURE REVIEW

The control of people deemed "dangerous" has gone on throughout the world's history almost everywhere. Generally, it is in response to something perceived as threatening to our society, something that should be rooted out and corrected for the benefit of all. Those who get to determine what is 'dangerous' and what is not is somewhat limited. Monahan and Geis suggest that, "The label "dangerous" often has been applied in America to persons whose major threat lay in the fact that they offended the moral or aesthetic sensibilities of those holding power" (Monahan and Geis, 1976: 142).

The label also tended to work in favor of the dominant class by ensuring some type of economical or political reward (Rusch and Kirchheimer, 1939). An historical example of this would be the labeling of African people as "uncivilized" and "wild" in order to justify enslaving them in the U.S. (Monahan and Geis, 1976).

The literature on the practices of confinement of people deemed "dangerous" is varied and plentiful from a variety of disciplines including anthropology, criminal justice, public health, sociology, and women's studies. From this literature there emerged essentially four groupings of works related to confinement. The first has to do with the types of people deemed dangerous, for example, the insane. This section describes the shifting focus of society on whom or what is dangerous depending on the historical context. The second type of work deals with critiques leveled against the practice of confinement whether they are ethical or functional. This makes up the most substantive part of my research because in dealing with critiques, we see a strong focus towards social activism (Robinette and Long, 1999; Silver, 1995), race relations (Gurney, 2000; Gussow, 1989), and economic utility (Worboys, 2001). Many of these arguments are similar to those I use in my discussion of segregation of HIV positive inmates. The next group discusses

methods of confinement and the perceived outcomes. Here, we see Bentham's idea of the Panopticon as a method of confinement (Foucault, 1975) or practices of total exclusion such as leprosaria (Gussow, 1989; White, 2003). Discussions of methods of confinement contain an historical thrust as well as we move into the present day and technologies and policy have changed. Last, we look at justifications for confinement. These range from religious (Monahan and Geis, 1976) to medical (Clements, 1989; Gani, Yakowitz and Blount, 1997). All of these works focus around studies of people who have been confined, yet the perspective and the focus differs somewhat.

# Dangers to Society

People who are deemed dangerous in society have been those who are regarded as deviating from the norm of the accepted ideology of a particular time period. This can be in regards to health, race, class, or political affiliation. The literature on the types of dangerous people throughout history is so extensive that there would be no way to describe all the instances in a single paper. Some of the most plentiful literature details the confinement of people deemed "insane".

In Foucault's *Madness and Civilization* (1965) he chronicles the rise of the asylum in the modern day and the way in which the lines between who is "crazy" and not are connected to the hegemonic powers in place at the time. People who are insane can be so for a variety of reasons, and, as some literature suggests, people can be confined and then essentially forgotten about. In his study of state psychiatric units, A.S. Kanter discovers the masses of elderly people who have been sent to live out the rest of their lives within these hospitals (Kanter, 1991).

Other examples of problematic confinement abound in the Victorian Era when many people, specifically women, were confined to the asylum for reasons such as "hysteria" which

may not be a viable reason today (Foucault, 1965; McCandless, 1983). People who are "insane" are confined to state hospitals, which used to be called asylums, and left there to undergo many types of psychiatric treatments in order to reverse their behavior, even though many times treatments can be invasive and not rehabilitative (Silver, 1995).

Sick people are also confined and this practice goes back to the very beginnings of the international public health movement. The practice of quarantine in the fourteenth century was helpful in stemming the spread of diseases such as smallpox and cholera (Merson, Black, and Mills, 2006). Foucault describes the atmosphere surrounding the plague when it appeared in towns during the seventeenth century and how all residents were confined to their homes and not allowed to leave unless a family member became ill in which case they had to leave to let their homes be purified (Foucault, 1975). Both Gussow (1989) and White (2003) discuss how people with Hansen's disease, or leprosy, were deemed dangerous by society and confined to leprosaria in places around the world. Gussow notes that the creation of leprosaria in the late nineteenth and early twentieth centuries in the United States and in colonial holdings had more to do with Western fears of the "other" than with the disease itself, which was already suspected by leprologists to be only mildly contagious. Today we can think of the segregation of HIV positive inmates as reminiscent of the leprosaria and Clements (1989), Zaitzow (2001) as well as scores of others, especially in criminal justice have discussed the parallels of the two diseases and those affected by them in their commentary on the strength of social stigma associated with the HIV/AIDS.

Angel-Ajani's 2004 study of Nigerian women in an Italian prison describes those who are dangerous because of political affiliation and family background. In this same vein, we can look at those people throughout history that became dangerous to the existing hegemony because of

the threat of usurping their political power. Here we can look at Gurney's study on the confinement of those working against apartheid in South Africa (2000). Paul Farmer talks about the confinement of HIV positive Haitians at Guantanamo Bay in his book *Pathologies of Power* (2005) as an example of a policy of confinement that is largely a political one. In his book he describes how the logic of quarantine in Guantanamo Bay was used to facilitate the new American-backed government in Haiti by detaining refugees in a place beyond U.S. or international law (Guantanamo Bay) and then returning them back to Haiti. By portraying Haitians as "dangerous", Americans were able to stop an influx of refugees from entering their country while at the same time working with the new oppressive Haitian government.

As we move into the present day, dangerous criminals are increasingly overrepresented in minority groups such as African Americans in the prison system. In his 2000 book, Christian Parenti describes the steeply rising rate of incarceration of African American males in this country which many others have described as a response to economic and political upheaval in the sixties and seventies. The "dangerous" people now fit an incredibly narrow stereotype that has its roots in racial and social tensions (A. Davis in Gordon 1998/1999; Currie and Wacquant 2000). From this very small store of literature, a pattern begins to emerge with regard to how society deals with its "dangers" and what these "dangers" represent to those who hold the power to decide.

#### Contradictions of Confinement

In every time period and for a plethora of reasons, people are confined because of real or perceived risk. This risk creates a highly concentrated area of exclusion and fear. Lorna Rhodes quotes a U.S. prisoner who writes, "Most Americans remain ignorant.....that they live in a country that holds hostage behind bars another populous country of their fellow citizens" (68).

These practices of confinement can be highly problematic because they symbolize some deeper agenda as it plays out through the rationalization of social isolation as the way to protect from social danger. In the next section of literature I focus on the critiques leveled against it. There are many layers to the practice of confinement and with every justification of exclusion we see an underlying discourse of power at work. In some cases, it seems obvious, for example, enslaved people from Africa in early U.S. history. Others, however, are not as evident and it is here we look to a body of literature that problematizes the effects and the rationale for confinement.

Most significant for my research is the body of literature critiquing the prison system in the U.S. as a place that "performs a kind of social, economic, and political "magic" by disappearing large numbers of poor and minority people" (Rhodes, 2001: 67). By socially embodying a criminal as an African American male, the dominant powers in this country can reproduce racism and turn away from seriously engaging the economic disparities that exist in our country (Currie, 2003, A. Davis in Gordon, 1998/1999; Parenti, 2000; Sloop, 1996). This practice of disappearing people is also discussed in earlier texts on leprosy. World powers would use the threat of leprosy to contain unwanted people and colonize their countries. By linking the ideologies of Christianity, Western medicine, and colonization, the U.S. and European nations were better able to control countries they were in (Gussow, 1989; Worboys, 2001).

Still other critiques have agendas for reform, especially in the prison where I focus my research. Confining people based on one specific trait, for example, having leprosy or having an HIV positive status is assuming these people all have the same types of needs which puts at a disadvantage those who wish to be cured or reformed (Clements, 1989; Robinette and Long, 1999; Zaitzow, 2001). These examples speak of acts of confinement as rooted in something that is outside of the realm of helping an individual. In her 2004 study of solitary confinement in

maximum security prisons, Lorna Rhodes argues that this undermines the rationale that confinement will somehow rehabilitate. Instead she questions these decisions by exploring what it means to be a social being. By focusing these critiques on the underlying motivations the hegemonic forces have in confining people deemed dangerous, scholars, public health officials, and activists can bring to light the irrationality that exists in the supposed logic of confinement.

This is not to suggest that all confinement is bad and that there is not sometimes a need for it- for example, in the case of an epidemic. Mostly, these critiques are leveled at the institutions themselves which have grown out of an ideology that these scholars perceive as unjust. Besides just a critique, many of these works give examples of ways things could be righted and a change of policy enacted (Gussow, 1989; Gani, Yakowitz, and Blount, 1997). In both of their studies, (Clements, 1989) and (Robinette and Long 1999) present ways to deal with the issue of segregation of HIV positive inmates while respecting human rights and focusing on rehabilitation and education. Still others argue for a look at the change in the role of the researcher to one that is more politically engaged and socially responsible (Angel-Ajani, 2004; Hatley, 2000). In describing the problems many people also detail the methods of confinement used as a way to represent the sometimes cruel act of confining a person.

All of these critiques are useful when exploring the choice to segregate HIV positive inmates within the prison system. It traces a history of the practice of confinement that illuminates the underlying agendas of those in a position of power. In my own research, I argue that, in addition to historically not being effective, confinement is more of a measure of social control than it is a way to protect or rehabilitate. These critiques pave the way for more examples, and more critiques, of this common practice in state societies.

#### The "How" of Confinement

When we look at methods of confinement, many times the image of a criminal behind bars emerges. This image defines a method of confinement in our country that not only confines a body, but controls it as well. The method of discipline in confinement is one in which those confined are individualized and named. They are stamped and classified as useful or not. By leaving them alone and solitary, the body is broken down so that it may be rendered as useful (Foucault, 1965 and 1975; Rhodes, 2004). Examples of this method of confinement are maximum security prisons in modern times or the plagued village in the Middle Ages. Here we see a move towards something useful and rehabilitative. However ineffective this method has been, the original goal was to produce a docile body through the method of discipline. This is in contrast to what White discusses in the leprosaria in Louisiana and Brazil (White, 2003). Here the method is total social exclusion. Individuals become faceless in the outside world because they are all one and the same. Made to live on the liminal edges of a society, they represent a body that is no longer useful and therefore cast aside and forgotten (Gussow, 1989; Kanter, 1991). In Gussow's book, we see that this method is sometimes tied very strongly with missionary efforts which in turn assign the disease a Biblical stigma.

Total social isolation combined with the method of discipline seems to be where the segregation of inmates stems from. In one aspect, the inmates are individualized and classified within the U.S. prison system. Their daily routine becomes cyclical; the series of gates and locks they must go through to reach the outside begins to subject the body to the anonymous tasks it performs day in and day out. In this way, the body becomes obedient and disciplined. However, the practice of further confinement within the prison and the exclusion from other non-HIV inmates is reminiscent of a leprosarium of sorts. This exclusion makes them faceless and at the

same time labels them individually as "dangerous". As Lorna Rhodes puts it, the fact that they are so incredibly excluded adds an extra layer of danger to them even after their bodies have become subjected to the daily routine of their lives (Rhodes, 2004). She goes on to say that, at times, this type of exclusion has the opposite effect on a body and actually works against them. By denying these prisoners agency, they sometimes cling to extreme forms of behavior as their last resort to exert themselves socially (Rhodes, 2004, 43-49). The "how" of confinement carries with it a set of assumptions that can never be totally effective because they involve human beings whose behavior cannot ever be predictable.

# The "Why" of Confinement

The last body of work deals with justifications for confinement. During the early years of the international public health movement, the justification for confinement was to seal borders against unwanted and easily transmissible diseases such as cholera Merson, Black, and Mills, 2006). Ships were confined in harbors for several days until it was thought they were safe to come in. Looking again at Paul Farmer's book, we see the justification for detaining Haitian refugees framed in a similar context. Diverting from health a bit, confinement was also seen as a way to protect the rest of society from physical and violent harm from people deemed insane (Monahan and Geis; 1976: McCandless, 1983) or sexually deviant (Minow, 1949). Still others had a more religious thrust. Again, to use the example of leprosy as a disease of the sinful, those who were infected were confined and mostly cared for by religious organizations (Gussow, 1989, Worboys, 2001). However, the bulk of literature I looked at for this project discussed similar justifications behind the choice to segregate HIV positive individuals within the prison system.

Studies have suggested that prison is a veritable incubator for HIV infection (Bryan, 2006; Braithewaite, 1996; Zaller, 2007). Much of this literature reports that because HIV

prevalence is higher in prisons than elsewhere, this is the ideal place to concentrate interventions. Segregation theoretically offers an opportunity to introduce a program to a population in a more controlled setting. Another justification is that it is assumed that inmates engage in more high risk behaviors, such as needle sharing and unprotected sex, than do the rest of the population (Robinette and Long, 1999). Segregation of this population would enable corrections officers and medical staff to assess high risk behaviors or need for treatments. They would also be better able to tell what types of interventions should be in place such as counseling or educational programs. Obviously, the best or most obvious reason to segregate would be in order to stem the spread to other inmates and officers in the prison (Robinette and Long, 1999; Zaller, 2007; Zaitzow, 2001). Although many of these talking points can be contested, this literature focuses on taking this approach in the name of safety, whether it is the prison, or society at large.

The literature on confinement of persons is extensive and varied due to the fact that this has been practiced since the beginning of state formation. Be it the exclusion of a particular ethnic group, or discipline of enslaved people, or quarantine of the sick, this practice is closely tied with ideologies. Many forms of confinement are justified through the prospect of protecting society or making it better, but there is always the underside of inequality and power struggle that defines the Marxist conception of our society.

We can use this literature to explore where we have come from and look to find gaps or holes that have not been addressed. In my own research, I focus on the women themselves, how they are a product of the dominant discourse, and how they are at the same time able to resist this discourse. I want to listen to their stories to find out how they struggle against a double stigma of crime and disease and how this defines the person they become. Much of the literature written on the segregation of HIV positive inmates focuses on men and is much more quantitative. The

experience of women in prison, I believe, cannot be the same and therefore warrants its own study. In contributing my own literature, I want to look at how women are confined not just metaphorically within a patriarchal society, but how that translates into life behind bars.

#### 2. METHODOLOGY

#### Epistemology

The question of authority is one that plagues anthropologists and other researchers who work with flesh and blood subjects, especially ones exposed to subjugation and trauma. An anthropologist has to give up the idea of participant observation in a place that has not only metaphoric, but actual bars dividing the researcher from the prisoner. Lorna Rhodes warns, "To forget one's position as an outsider is to be in danger, not only from interpersonal trouble of various kinds but, more enduringly, from alarming emotional and intellectual identifications" (Rhodes, 2001, 76).

As much as I would like to believe that armed with my theory and my critical stance of the prison system I could go into those walls and somehow desensitize myself to the dark, cold, and unjust world of the prison would be very naïve on my part. Conversely, to go in and romanticize the experience, I believe, would be unfair to the women who have shared their stories with me. The question then became what my role as an anthropologist would be and how I would be able to establish any authority to make a truth claim that could satisfy both the women about whom I write and the academy for which I write. Keeping this in mind, my research was aimed at working collaboratively with women who had already been released from prison. Although working in the prison would seem to be the ideal, it helps to remember that my position as "on the outside" connotes not only problems of authority but also the type of knowledge I would be able to obtain.

Jayati Lal (1996) describes the fieldwork experience as one that should be engaged with "the politics of location" (Lal, 1996: 102), which discusses how identity for the researcher becomes fluid depending on the context she is in. It becomes important, then, to look at our

subjects in terms of the things they may want to present to us and how their agency acts to dissolve boundaries between researcher and subject. Narayan (1993) also discusses the perceived divide between a researcher and her subject when she discusses the "native" anthropologist. The use of the term native to denote some type of similarity between you and those you study can be problematic because it essentializes those whom you research by assuming they are all the same. For example, by segregating all HIV positive female inmates, we ignore the fact that these women are all individuals with different needs. As a researcher, it is important to be aware that even as we try to speak for those "natives" we research "that 'we' do not speak from a position outside 'their' worlds, but are implicated in them too: through fieldwork, political relations, and a variety of global flows" (Narayan, 1993: 676). In my research, authority will come from looking at the site as the context through which my identity and the inmate's identity is constructed. On the outside of the prison we find a space that becomes more level. Lal also warns against dwelling too long on the question of authority when she states, "In an era of rampant reflexivity, just getting on with it may be the most radical action one can take" (Lal, 1996: 125). In summation, it is important for me to be critical of the authority I have to speak about these women in the field, but by acknowledging this divide between "me" and "them", I can attempt to work between the lines.

We can start by looking at the type of knowledge that is produced, experiential knowledge, as the basis for a truth claim. In *The Evidence of Experience* (1989), Joan Scott problematizes using experience as a source for knowledge. She argues that there is no experience that is not already mediated by social constructions so "experience" is preconditioned. She states, "Experience is at once already an interpretation *and* something that needs to be interpreted. What counts as experience is neither self-evident nor straightforward; it

is always contested and always therefore political" (Scott, 1989: 794). We can look to experience as a way to understand the complex process through which knowledge is produced and lived. But because all experience is not universal, we must be careful to present it in a way that does not assume that, as Angel-Ajani puts it, "the amorphous space known as the field is level" (Angel-Ajani, 2004: 140). Paul Farmer describes conflicting accounts of the same experience dealing with Haitian refugees in *Pathologies of Power*:

Accounts of what happened there conflict, even when offered by eyewitnesses. The version offered here- that of the detainees..... differs significantly from the accounts offered by journalists, U.S. government officials, and even the Haitians' lawyers (2005: 54).

My choice to interview women who have been released allows me to have much more freedom to discuss not only the answers to my questions, but also the thoughts that shape these answers. During the process of writing my IRB, I began to realize how difficult it would be to have any real freedom to explore the experiences of women who were locked up. They were caught up within the dialogue of the prison, their lawyers, and other prisoners and the information I received would be filtered through that lens. In entering the Italian prison where she conducted her fieldwork, Asale Angel-Ajani was struck at how routinely the women in the prisons answered her questions (Angel-Ajani: 2004). With all the work done on prisoners over the years, it seems hardly surprising they would be used to another researcher coming in to ask questions. It is important to remember that a person's answer will always be colored by what they believe you want to hear and also how they choose to tell it and by how secure they feel in answering your questions.

In her 1988 essay, *Situated Knowledges*, Donna Haraway she reminds us that factors like age, race, gender, and class will significantly influence the kinds of information we receive and

produce. She writes, "I am arguing for politics and epistemologies of location, positioning, and situating, where partiality and not universality is the condition of being heard to make rational knowledge claims" (Haraway 1988: 589). We could argue that all knowledge is situated or positioned, but some forms are less biased than others and if we can see this, we are able to question privilege and power dynamics. Thus the knowledge we present as truth can be viewed through this contextual lens as a view from the ground level and not from above. I believe in this way, I can say something valid about the experiences of the women in the prison and connect this to some broader truths about the connections between power and knowledge while at the same time remaining critical of my own experience.

#### **Ethics**

Working with vulnerable populations such as prisoners is always tricky. The question of ethics will inevitably come up as these populations ride a slippery slope between what can be perceived as harm and good. During the IRB process, so many possible forms of exploitation were presented to me during my correspondence. The idea that I had to justify every action I made, whether it seemed small or not, was taxing. There is a strong potential here for error when working with a population that has become stigmatized and therefore vulnerable. However, it seemed to impede the process of any real data collection because so many things had to be explained. I began to question the very idea of ethics beyond institutional liability. The age old ethical guideline of "do no harm" is just as important a consideration today as it has ever been but it is important to remember that "ethics" also goes beyond the typical institutional guidelines set down by the university. Perhaps the first place to start would be to think about the motivations and aims of my work. I would be lying if I said I had no political agenda and I with

believe to gloss over this fact just to appear unbiased would invalidate my work. I tend to agree Angel-Ajani when she argues:

I hoped that I was more than just a narrator of other Black women's lives. I hoped I was more than just a mere anthropologist. I believed that I belonged to a group of activist-scholars who, through writing, research, and organizing, were working toward the abolition of prisons as we know them and, through this process, exposing the broader racist, sexist, and classist social structures that criminalize and demonize poor Whites and people of color (Angel-Ajani, 2004: 134).

Angel-Ajani argues for something called activist anthropology which combines academic scholarship with political engagement so as to render the work we do more useful in a broader context. Sometimes this form of engagement is used through the tactic of "witnessing" (Rosen, 1977). The act of witnessing happens largely when there is some sort of oppression, injustice, or outright violence that an anthropologist observes in the field. Rosen discusses the problems that arise when anthropologists are called on to give their witness as testimony in legal cases which turns them into a part of the system that may have dire circumstances for the people they study.

These dredge up images of a courtroom in which one is asked to recite facts without stating a bias or questioning the conditions which produced their work in the first place. In this way, we become one more juridical arm in a long list of social scientists, psychologists, and even police called to give our expert opinion on what we see happening in the situation. In *Discipline and Punish* (1975), Foucault chronicles the move from the elite judge handing down punishments, to the division of the judge into many parties all deciding an individual's fate. By participating in the decision making, we become a part of the institution we criticize in our works. This rouses suspicion in those we study. Instead of being a witness devoid of any ethical obligation, Hatley writes that our responsibility should be first and foremost to our subjects:

Burdened by the other's suffering, we are called upon not only to understand or, at the very least to give a historical record of a particular act of violence, but also and in the first instance to witness it. By witness is meant a mode of responding to the other's plight

that exceeds an epistemological determination and becomes an ethical involvement. One must not only utter a truth *about* the victim but also remain true *to* her or him. In this later mode of response, one is summoned to attentiveness, which is to say, to a heartfelt concern for and acknowledge of the gravity of violence directed toward particular others. In this attentiveness, the wounding of the other is registered in the first place not as an objective fact but as a subjective blow, a persecution, a trauma. The witness refuses to forget the weight of this blow or the depth of the wound it inflicts (Hatley (2000) in Angel-Ajani (2004): 138).

I give all this information about witnessing violence and ethics because of the reputation our penal system has in this country. The particular prison the women in my study have come from has come under fire in the last several years for mistreatment of their inmates and my work will reflect not only their impressions of this violence but my interpretation of it.

However, it was important to me to be wary of going in with too many assumptions. I did not want to begin fieldwork as if I already knew what the situation was and conflate my data to fit my theory. Angel-Ajani advocates the simple method of listening to find in the prisoners what they believe is important to talk about. In this way, I hope I have stayed true to my subjects by working with them to give voice to the way they view particular policies or events.

I also realize that in taking an activist approach I may run the risk of angering those in authority within the prison and, therefore, harming inmates who remain incarcerated within the walls. That is why I am making the choice to interview inmates who have been released so that no one can be victimized. This may do little to alleviate the situation in the prison. Lorna Rhodes diffused the tensions that existed between the guards and the inmates by using different words when speaking from various perspectives. For example, the word for those who work within the prison can be "officer" if it is coming from the worker and "guard" or "cop" if it is coming from the inmate. This added a dimension to her work that represented these differences but didn't favor one over the other (Rhodes, 2004: 9). I believe there is a way to use language in a way that

allows you to still get your point across but not fault any one particular party. Not *all* guards are abusive just as not all *inmates* are violent.

Finally, in discussing the issue of ethics I would like to cite Rolls' (2003) paper on being an ethical researcher to stress the idea that there will always be something that you cannot plan for. Inevitably, you will encounter some situation in which you must make a decision whose outcome may not be beneficial to all parties. Assuming that you know everything that will come of your research both in the present and the future would be arrogant and so to do the best you can and expect for changes is wise. In the course of preparing to do this research, I have run up against many ethical dilemmas because of the group I have chosen to work with. In his paper, Rolls states that the ethical issues we are faced with today are constantly in flux and that in several years the choices we make may seem unethical to those in the same field. Take the example of Humphrey's (1970) work in public rest areas in which he observed anonymous sexual relations between men in a public restroom; although at the time it was lauded as important foray into an extremely taboo topic, today we hold it up as an example of what not to do in research. I do believe there are some ethical approaches that are constant however, such as minimizing harm to the women I work with, and this idea that is tied up in the IRB process is one that also aligns itself with my personal ethics as well.

The experience of writing an IRB for the first time has been very frustrating at times. I found that the IRB is actually more geared towards research in the hard sciences and so it became difficult to discuss my methods and the knowledge produced by them within a positivist framework. The very idea that any data I produce would not be irrefutable highlights the differences with working with flesh and blood human beings without the luxuries of a control group or any variables. This research has its footing in the human emic experience and however

different each may be, my job as an anthropologist is present both the emic perspective and to assign etic meaning to say something collectively about the experiences of these women in a broader context. This chapter outlines the ways in which I find a tentative authority. It also navigates the ethical dilemmas that constantly come up. Although my IRB is finished and passed, I still have my own personal ethical guidelines to consider.

#### 3. RESEARCH METHODS

The U.S. prison system began housing HIV positive inmates in segregated facilities during the 1980s. The choice to do this was mainly fueled by misinformation about transmission and the general social fear caused by an epidemic (Clements, 1989). As AIDS education campaigns have spread, less fear remains in society; however, U.S. prisons have lagged behind the rest of the country. An important reason for this is the high rates of HIV positive inmates in relation to the rest of the population generally because it is assumed that incarcerated people are more prone to high risk behaviors such as needle sharing and unprotected sex (Braithewaite, 1996).

Additionally, a disproportionate number of African Americans are in prison and they have shown a very high prevalence for HIV infection in the last decade or so.

The choice to segregate is made on a state by state basis, and currently there are three states that segregate as well as severely limit these inmates' access to work programs, medical care, and the rest of the prison grounds (Zaller, 2007). Women present an even more interesting case in that the rates of HIV infection have risen in the last several years while the budget for women's healthcare has remained low (Zaitzow, 2001). Although rates of intraprison contact remain low, women generally demand more treatment, physical and otherwise, than their male counterparts. Evaluations of segregated housing units show psychological effects related to stigma and isolation (Clements, 1989) and women disproportionately suffer from these psychological effects. In my research, I aim to look at the experience of the women within the segregated facility and how they embody or resist the stigma placed on them as females, prisoners, and HIV positive persons.

#### Location

I conducted my fieldwork in relation to a women's prison in Alabama that still segregates inmates who are HIV positive. The choice to use this prison stems from its proximity to my home as well as the fact that they have come under fire recently for their treatment of prisoners in the HIV housing. In November of 2004, this prison finally granted more access to these inmates by allowing them to participate in substance abuse programs, educational programs, and medical programs. However, they are still segregated and denied full access to programs such as work programs, which can significantly reduce their sentences. This makes it part of the only prison system in America that continues to deny these programs to HIV positive prisoners.

### **Participants**

Through my work with human rights non-profit organizations, I have been able to gain access to these women. I anticipated through my prison work with the Georgia State University's Institute for Public Health that it would be difficult to locate women who have been released. The program director at the Department of Corrections had mentioned how difficult it was to keep track of people who had been released because they would skip appointments once outside or find themselves back in the system. I was pleasantly surprised at the willingness to help that I received from the head of the prison project at the NGO. I got the feeling that both the eximmates and their lawyers had been empowered through the judicial process and was more than willing to talk about this "archaic practice" as one woman so eloquently put it. Obviously, my agenda was similar and as much as I tried to remain neutral, I was taken with how energetic the whole team was and by association, I became involved as well.

This organization has been working on the situation in this prison for almost seven years and made great strides at the overturning of the policy of exclusion from prison programs for the

inmates in 2007. They work on a number of prisoner's rights cases and have had some major successes in the process. The first time I spoke with the head of this project, we talked for almost two hours on the phone. She was so knowledgeable and I could detect something like anger for the way the prisoners were treated. Above all this, I could tell she was dedicated to this project and excited to tell anyone who cared to listen what the prison system in the U.S. was like. After first contacting the women and obtaining permission herself, she then offered numbers up to me. This process began a snowball effect in that each subsequent woman gave me the contact of another woman and I was able to build a solid group from which to draw information. My affiliation with this non-profit group was the common link these women and I initially held and I believe it was this association that helped me to gain access.

#### Methods

The methods I used were mainly focused on observation, interviews, and conversation. Obviously, I could not be a participant observer inside the prison or in any other way. These women lead relatively normal lives now that they are released but by talking about their past experiences in depth, they can recall images of what that period was like for them. I used loosely structured interviews with four former inmates for a total of nine interviews. This choice is based upon the fact that my research question was very open ended and I wanted enough freedom in the interview to spend time on whatever we touched on that was of importance.

Most women had at least two interviews with me and some had more depending on their availability. The majority of these interviews took place at the homes of the women. Sometimes informal interviews would take place when I took them out to run errands or we went to dinner at a restaurant. Oftentimes, we would have to reschedule interviews due to the fact that the women were busy at work or at a clinic or moving. For women who have just been released from prison,

as was the case with two of my participants, there are many ends to tie up in order to secure their place on the outside. They must find jobs, housing, file for disability, or find family members.

Additionally, all of the women in my study volunteered at organizations designed to work with HIV positive inmates. Because of their busy lives, phone interviews were sometimes the only way to move forward.

My questions began with an exploration of the process of confinement. For example, I asked them what the disclosure of HIV status was like for them and how it felt to be segregated from the rest of the population. These questions provide a base to talk about the beginnings of the act of internalization. I did not ask anything regarding how they came to be there unless they choose to tell me. To me, this would have served no purpose but to situate that person's testimony within the moral judgments of her crime. From there questions focused on the "naming" of certain activities and daily routine. What was a typical day like, and describe the building you were in, or what was the medical care like, were questions posed to the women to get an idea about the dialogue that went on in the prison. The next sets of questions were more in depth and focused on their impressions of the facility, their treatment, and their life post release: How have these experiences shaped their identity? What happens within the prison in terms of resistance? What is the experience of one who suffers from the double stigma of being HIV positive and an ex inmate?

I elected to use a tape recorder in my interviews so that no part of the interview was lost. For protection, I transferred the taped sessions to my password protected personal computer. I was then able to transcribe directly from my computer. In follow-up interviews we were able to go through the last interview together and clarify important points or explore particular topics

more. I was interested in looking at how they embody or resist the discourses of power that shape their lives.

Obviously, the observation was just that. This came mostly from working with the non-profit and observing reactions of women to my questions. This helped to inform the dialogue between myself and the women I interviewed. In doing this, I was careful of not providing any identifiable characteristics beyond facial expressions and minor characteristics. Although I can never *really* say with any authority what it feels like to be in prison, I can at least be reflexive about my own feelings and those of the former inmates and NGO workers.

#### Drawbacks

I went into this research aware of my limitations, but confident that a good study could be produced. My goal, here, is to offer an alternative to the dominant discourse on those who are female, convict, and HIV positive. These women have varied histories, different needs, and unique situations. To lump them all into one homogenous group says a lot about the way society stereotypes according to only one or two particulars.

By using experience as a way to knowledge and by situating that knowledge within the context of the prison, I can say something about the way people internalize and are products of their history and society. The ethical considerations are many and I proceeded with caution but also a sense of responsibility to the women I work with. I had to go in with trepidation because I did not want to assume too much about what I think I may know. As Lorna Rhodes suggests,

The task of steering between abstract and fetishized representation is delicate, but it contains the possibility of a necessary confrontation with the brute facts of domination as they play out in institutions that have become ubiquitous, if partially veiled, features of our cultural and political landscape (Rhodes, 2001:77).

### 4. STIGMA, VISIBILITY, AND THE INTERNAL GAZE

I just couldn't understand because there was so much going on at once. I got the three year sentence; I am on the segregated unit because I was HIV positive.... I didn't know what to feel, I was bombarded with feelings. (Juliette, 35)

This comment by a former inmate at Tutwiler prison highlights the emotional difficulties faced at the intersection of several social stigmas to which she is now subject. The way these women choose to react to and reshape their identities according to this unique situation must begin immediately upon knowledge of their placement in a segregated ward for HIV positive inmates only. Upon entering prison all inmates exist in a type of limbo while they wait to be medically cleared. Whether they are aware of their status or not, the shock of being "thrown", as one inmate describes, onto the medical ward automatically causes them to renegotiate themselves in relation to an identity group that inscribes them as not only diseased, but dangerous. Lorna Rhodes describes this first act of separation from the group as the most glaring effect of their stigma. In her book on maximum security prisons, she notes that segregation shapes the way that those who are not segregated view the person. In this way, they are linked with danger and mystery and therefore turn into the "monsters" they are perceived as. Rhodes suggests, "The more tightly a prisoner's body is controlled, the more his production of language comes to seem autonomous, seductive, and threatening" (Rhodes, 2004: 165).

The medical ward at Tutwiler prison, which also came to be known as the "AIDS Colony" (Fleury-Steiner, 2008), carries a lot of social information and assumptions about the women living there. It affixes a social stigma by showing a visible sign of the shortcomings of the HIV positive female inmates. The act of locking them down in their own ward and denying them access to population and programs is an example of how this type of segregation suggests that they are "contagious" or "very sick". During the 1980s, when hysteria over the epidemic

was at a peak, these visible signs echoed the mindset of much of society. One former inmate told me:

Before my time as an inmate it was a whole lot worse when officers would wear masks before even coming back there on the unit. It was far worse and many women died before my time because conditions were far worse.

Whether or not these signs are necessary is an important point and many believe the intent of segregation has more of a negative effect than a positive one. This chapter explores the effects of this stigma and how the women begin to accept and integrate it into their lives when it is so readily visible to all. It also looks at how this stigma affects social relationships with those that share their stigma and those they come in contact with.

## Accepting and Integrating Stigma

In his comprehensive work on the subject of stigma, Erving Goffman (1963) describes several patterns of socialization in regards to an individual learning of their particular "shortcomings". As stated earlier, this has an almost immediate effect on their conception of self in relation to others and how they will incorporate this new knowledge into their lives. One such pattern occurs when:

Such an individual has thoroughly learned about the normal and the stigmatized long before (she) must see (her)self as deficient. Presumably (she) will have a special problem in re-identifying (her)self, and a special likelihood of developing disapproval of self (Goffman, 1963: 34).

The question then becomes what their perception of the stigmatized group was before they realize they are a member. Where does their information come from and who is supplying it? Finally, what is their response? In dealing with these questions, we must first look at how the gaze on inmates, females, and HIV positive persons is constructed and how, by internalizing this gaze, these women may develop what Goffman describes as "disapproval of self".

Visibility and Media Representations

In his book, *The Cultural Prison* (1996), Sloop discusses this concept of the prisoner from the point of view of the rest of society. He argues that media representations and commonly accepted generalizations of prisoners function as a way to represent that which is unacceptable social behavior and therefore reproduce and naturalize societal norms. He writes, "Hence, while a representation of a woman or an African-American male prisoner, for example, might be different than the 'empirical reality', it cannot be outside of what is ideologically acceptable to a great number of people whom advertisers wish to reach" (Sloop, 1996: 11). Both Parenti (2000) and Sloop discuss about the public image of an prisoner as extremely racialized which produces a stereotype of African American males as criminals. Here we see evidence of how several types of stigma are intertwined so that one form of stigma, based on racial identity, can imply something else about the person such as that they are criminals. This is particularly true when looking at the stigma surrounding HIV/AIDS because having HIV/AIDS is still sometimes largely seen as a result of moral transgression instead of a disease that kills indiscriminately. One former inmate I interviewed blamed the ignorance in the South for the stigmatizing attitude and was shocked at the discriminatory practices that she encountered in Tutwiler, her voice raising to almost a shout as she expresses her frustration,

I thought it was just cruel to segregate us. I didn't know that in the U.S. you could get away with things like that knowing that the ADA [American Disabilities Act] forbids.... You cannot discriminate against a person who has any disability or medical condition. Knowing we have all these things in place and yet in Alabama we can get away with it. It is embedded as a moral disease in Alabama. It's looked at as if you did something to get it or you committed some kind of sexual immorality for you to obtain it. All of these things entwine with each other (Tasha, 25)

One of the most disturbing things to Juliette, a former inmate at Tutwiler who was released in 2002, coming into the HIV ward already knowledgeable about HIV was the number

of women who expected nothing from the staff. Because they had accepted the mass media idea that the HIV issue was a moral one, they lived in a state of denial that made them hard to reach at first. Juliette struggled to help women realize the importance of their medications even though they rarely listened: "The stigma was so huge they wouldn't wanna talk about it. I (Juliette) began to realize that the fact they were in prison and their emotional ability was unable to comprehend at that time". The images women saw on television and in photos of prison life and HIV/AIDS patients played a part in informing their opinions and perceptions just as it has the majority of society. However, it became clear to me during interviews with them that it was not necessarily that the women held the media images to be true, but that they were keenly aware of how others would view them based on these stereotypes that are based on misinformation. Most of these women had received their knowledge of the disease based on programs in their communities that targeted the African American female drug user demographic into which the majority of these women fit.

## "A Community Issue"

The women in my study were all well aware they were at high risk for HIV infection before they were diagnosed. HIV/AIDS related stigma often has to do with assumptions based on socioeconomic status, race, and gender which has influenced policy decisions and community based educational programs. Because African American women represent the new face of the infection in the United States replacing homosexual men in terms of the highest incidence of infection, many programs target them as the point to begin prevention services. Marilyn, another former inmate who was recently released in early 2008, told me that her preacher had already told her about the possibility she was HIV positive based on her drug use and her race and gender. Marilyn was tested prior to becoming incarcerated and believed she was taking the

proper steps to prevent her infection. I began to think about the scope of the HIV/AIDS prevention and education programs and noticed that they do a lot in the way of helping to prevent spread in a statistically high risk population, but they do little to alleviate the stigma associated with the disease in populations in which the incidence is relatively low.

As a white, middle to upper class female going to a private elementary school I would have had no exposure to the issue of HIV/AIDS when I was young had it not touched someone close to my family. When Juliette and I speak about the neighborhoods we grew up in, I began to realize how even the prevention programs could be viewed as stigmatizing by only targeting poor black areas for involvement. However, Parker and Aggleton point out that

Focusing on programs for the "general population" may also reinforce the perception that it is less important to protect populations that practice "high-risk" behaviors than the "innocent and unsuspecting" general population. It may also result in discrimination against marginalized groups; since those at greatest risk do not receive the resources they need (2002:7).

Certainly, as a community issue, Juliette was far more familiar with HIV/AIDS epidemic than I was. Juliette and I had an instant bond because of our passion for activism and our open and informal nature with each other. She almost always is smiling and at ease and has a way of speaking with her whole body and reaching out to grab your hand while making a point. Juliette and I were at her home one day speaking about growing up with a degree of knowledge about HIV/AIDS and how that related to initial feelings upon disclosure of her status:

Yes, it [education] had a major impact with me because my sister had HIV houses [which provide shelter, medications, counseling, and a social environment for people living with HIV/AIDS] when I was young so HIV was always a part of my life so I always knew about it, never thought I would get it, but when I did I had some reference to fall back on once I did get it. Plus, coming from Baltimore it was a community issue. You didn't have the luxury of how you felt and how you thought; you had to move straight into action because it was people you loved.

The women in my study felt the stigma of HIV positive status in two ways before knowledge of their own infection. On the one hand they are aware of societal perceptions of HIV positive persons based on mass media images. On the other they are aware that based on visibility related to the stigma they are already loosely associated with it. However, there is still a separation there. Up until this point the women saw themselves as "sympathetic others" in the sense that they are "normal but whose special situation has made them intimately privy to the stigmatized individual and sympathetic with it" (Goffman, 1963:28).

### Receiving

The point of diagnosis of HIV status is, most obviously, the moment in which these women start to deal with a new aspect of their self identification. While some women are aware of their status before being incarcerated, the state mandates that all women be tested upon entry. For the women in my study, the area of the Department of Corrections known as "receiving" was the first taste of their new life as inmates and HIV positive women.

Receiving is the point of entry for all women entering prison. It is often overcrowded with women waiting to be assigned to different prisons and medically checked out. One former inmate recalls how miserable the conditions in receiving were:

"I was in receiving and there they treat you like shit. I think because there are so many women and it's overpopulated and there is a lot more stuff going on that they have to watch for."

Receiving is also the first place in which you are stripped of your "old" identity and assigned a number for the duration. The women describe this process as the worst because guards are concerned with just turning over as many inmates as they can in a day so your individuality counts very little. The women whose blood comes back as positive for HIV infection are isolated within receiving for further testing and treatment if necessary before they are sent to the Tutwiler

medical ward. It is in Receiving that some women first learn of their HIV positive status.

Because of the overcrowding many women become very sick and their health continues to fail because of inadequate treatment. One former inmate stayed in receiving almost eight weeks with a staph infection from a spider bite. "I was literally on my deathbed", she said, before they were able to get to her for treatment.

Although each woman has a unique story, they all experience a sense of shock and helplessness in the face of their new status. Because of state mandates on disclosure of status and protection, only the prison doctor can tell an inmate her results. Prison doctors are not always on hand to deal with this sensitive issue for some time which results in inmates being detained in Receiving for long periods of time with no clue as to why. The doctors are also not required to give any sort of emotional counseling so many women are left to deal with this new information alone. Marilyn's story illustrates the difficulties faced by women upon hearing news of their status and the emotions associated with learning they possess a new stigma.

# Marilyn

Marilyn, a 33 year old African American woman, has been in and out of prison the most out of all the women I spoke with. She also seems to be in poor health. She has just recently gotten out of surgery for complications with her medication. She also drags her feet when she walks and breathes heavily. She has a little bit of cheekiness about her, and her bright red hair reminds me of her temper. I have a feeling she still is not yet sure of herself being just released last year, but she is actively looking for a job so that she can get out of her small apartment; "there are some nasty people that live here", she says. She found out she was HIV positive the first time she was locked up in 1997:

They come in and they quarantine us down. Then we go in the dorm (Receiving) with all the inmates and everything and then they pull your blood. And so about, I think, three

days after I got there they pulled my blood and so they called me out and told me to go back there to the medical area. So I went back there and then they told me go in this cell and so I went in the cell and they locked it up, you know, and they wouldn't tell me anything.

Marilyn stayed in the cell for a day and a half before the doctor got there. She received no counseling and when she asked the nurse to let her out to smoke and calm her nerves, she was told she was not allowed to go anywhere. This was the first experience she had with the segregation and treatment of HIV positive inmates in the system. With no one to talk with Marilyn was in a state of denial. However, she still laid hope on the fact that she had not gotten her Western Blot, which is a more specific test for detection of HIV antibodies, results back. The chaplain was the first person to come to sit with her and counsel her and they prayed together that her Western Blot would come back and she would be clear, but it was not. This moment is etched clearly in her mind as the point in which she was faced with the knowledge that she was a member of a stigmatized group and her reaction was telling of the mystery and stereotypes that still surrounded HIV/AIDS:

The first thing I thought was I am gonna die. This is gonna kill me. Because when the doctor told me, they put me on medication right then and so he put me on Serax and Atripla. And I cried and we prayed because they had a Western Blot and another test and maybe the test will tell you the truth and tell you what's going on. I was crying, I was crying, I was crying, I was crying, so the chaplain came over and prayed with me. It was just before Christmas too and I could hear them singing songs and they was praying for me that my Western Blot would come back clear but it came back and I was positive.

## Juliette

Juliette, an African American woman, who was 35 years old at the time of my interview with her, learned of her status when she was in jail. She was ordered to go to a drug rehab called New Life. This was a Christian focused organization that she claims really helped her to deal with her addictions. As one of the conditions of the program she and all the other women had to undergo a physical in which they were tested for HIV. She knew she was a high risk but had

never been tested and in the back of her mind she says it was always there that she may be positive.

My very first test came back positive so when they called me back to the health department to give me my results I knew. Because out of 17 women that went and had this test in this drug program I was the only one that they called back and it was a clear sign to me that I was HIV positive. And right away, instantly, this counselor, her attitude towards me changed. Right away everything in my whole life changed

Goffman writes: "the stage of experience during which he) learns of his stigma will be especially interesting, for at this time he is likely thrown into a new relationship to others who possess the stigma too" (1963: 36). The medical ward at Tutwiler is where all the women are sent after their HIV positive status is assessed. Most of them arrive in tears and confusion, either from learning they are HIV positive or from learning they will be segregated because of it. The experiences of the women on the dorm give examples of how one is treated by those who share their stigma and also by those "normals" with whom they are in contact. These experiences further shape their identities as they struggle with their sense of self worth and their visibility as "stigmatized others".

#### A Prison within a Prison

Until 2004, women who were HIV positive were sent to buildings in the back of the prison in the old building that used to be receiving. There were two dorms there: MIU1 and MIU2 plus the rest of the medical ward for population. Across the hall from their dorms the women with tuberculosis were isolated. One former inmate remembers how the women would call out to each other from across the hall or stand in the door and speak to them; "they were the only other people there and we were all bored so we talked to each other". The discriminatory policies regarding the confinement of these women made many of them internalize feelings of shame and hopelessness. This was further compounded by the boredom they felt in not having

any sort of outlet and one former inmate told me that, "The system just makes it worse than it really is. They make people retaliate or they don't give anything constructive to wanna redirect or change your life thinking. There is nothing for that, nothing." This boredom made many of the women feel like they were "tied up" and "in a cage". Many of the women began to feel apathetic and listless with nothing to do. For some of the women in poorer health, this had an adverse effect on their ability to keep themselves well. By internalizing the idea that they had become useless and thrown away, women began to die and "no one really put up a ruckus". One former inmate, Tasha, 27, described it in this way:

Just the part of not valuing the self, I mean black women from the South just don't have. In certain classes they just don't have a huge value of self or importance of self or an importance of taking care of yourself. It's almost like robotic. Whatever you say is good enough for me. If you tell me I'm nothing then I'm nothing.

# Ignorance and Policy

Dorm life in the medical ward differed significantly from the general prison population, which in prison jargon is just called "population" and to which I will refer from now on, until 2004 when they became integrated. They had no access to programs and no contact with population whatsoever. One inmate told me that if you were caught talking with population through the fence, you were written up and the entire dorm would lose yard privileges. Two of the women in my study served their time together and told me that the warden at the time was aware of romantic relationships between some of the women in the medical ward and in population and, even though there was a fence between them, was concerned that they may transmit HIV. "I mean you can't catch it from sneezing" one said, "it made me mad because of the lack of knowledge that the warden had about this". While scholars offer other reasons for this practice of confinement such as political (Farmer, 2005) and economic ones (Rusch and Kirchheimer, 1939), the women who bear the burden of lack of services concern themselves

more with the everyday task of gaining equal access and resisting the stereotypes associated with living with HIV.

One of the big complaints the women had about living "on the ward" was the fact that they were banned from eating in the cafeteria. Carla, age 27, is a former inmate released in 2006 who told me that although she didn't really feel the segregation policies were discriminatory overall, her one big example of how she felt she was treated unequally was related to the cafeteria policy. She says it bothered her because "of the fact that it made you feel like they thought they could catch HIV from us sitting around them or eating off their trays or silverware or whatever". Their meals were brought in on carts that "were stinky and nasty" and "roaches would crawl out". The women had no table to eat on so they had to sit on their beds with their trays in their laps to eat. Beyond the frustration with the irrationality of the system, being made to feel that they did not deserve to be treated equally went a long way in how they would view themselves. They often felt as if they were singled out, which in turn affected self esteem.

Although the women were kept away from population, the stigmatizing policies made their HIV status visible to everyone in the prison. Before 2004, the women were allowed one church activity per week and this was the extent of the programs available to them. During this time, they would lock the entire prison down and escort the women to the chapel. Marilyn has seen the changes in the treatment of HIV positive inmates and she recalls how it made her feel to be so visible yet so isolated at the same time: "When we went out on the yard or anything like that they locked the whole place down. It made me feel like I was a showcase. It made me feel bad... well it didn't make me feel bad but you know, everyone would look at you when you go down the hall". Being made to walk through population may have given these women the

feeling that they were being singled out, but I found that the social relationships they made on the ward were not all negative.

## Sympathetic Others

We have seen how the restrictions placed on the women in the medical ward contribute to feelings of isolation and shame. However, many of the women found solidarity in the other women on the unit because they shared the same stigma. Goffman calls this group of people *sympathetic others* (1963: 20). The women on the unit were helpful when dealing with the stigma because they offered firsthand experience. There is something about a woman "being able to share and speak form the heart" as Tasha says that offers a retreat for the women. Carla speaks the most positively about the segregation and focuses a lot on this feeling of solidarity that came from being able to share your stigma:

Emily: So you felt the segregation was helpful.....

Carla: It was because it helped me learn about it (HIV) and you learn from other people with similar things you are going through and these women had been through the exact same thing and are going through the exact same thing that I went through. At one time I was like well what the hell, I am gonna get out and go smoke some more drugs and continue doing what I was doing. What's the use of taking this medicine? I am gonna die anyway. Whenever I first found out and I was in isolation I was like well, you know, who cares about me who is gonna care about me anymore, you know, I have a disease, a deadly disease, nobody will want me and I just felt like I was useless and wasn't gonna have a life anymore. I just wanted to give up but when I got in the , you know, it gradually started to change because I saw women that have had it for 8, 9, 10, 20 years and they live a normal life. They sat down and told me life isn't over just because you got HIV and I see that they didn't give up and it changed my mind about giving up.

This is an important part of dealing with any sort of social stigma because it gives a person the freedom to feel normal. Goffman goes on to say that this type of sympathetic other can be damaging because it confines the person to "a half world" only made up of people like themselves. In the space of the prison, however, and with the lack of counseling services

available to the women, this was their only source of education and therapy at the outset and proved to be invaluable to all of them.

There is another set of sympathetic others I mentioned previously: the ones who, for whatever reason, are affected to some degree by the stigma. This can be family, friends, and in this case even the officers on the ward. Many of the women felt much better after they had disclosed the status to their families and found acceptance through them. They also mentioned the population as a set of sympathetic others and one former inmate said that although they were made to walk through population on lockdown it wasn't always a bad experience. Many of the women knew people in population so walking through generally meant you could shout greetings to the people you knew there. Because of the demographics of the prison in general, many of the women in population are at high risk as well. "They knew it could have just as easily been them because they are coming from the same place as you", one former inmate told me.

The women on the ward found a way to integrate their HIV positive status into the construction of their identity through the solidarity they found with the other women and guards on the unit.

By not allowing their HIV status to become central to their identity, they were able to focus on questioning the policies enacted on the unit without allowing themselves to become victims.

### 5. US, THEM, ME: POLITICS OF POWER AND CHOICE TO BE GOOD

When many of the women speak about the warden in the prison, they talk about the difficulties encountered when dealing with him or her (this depends on the time period, there were two wardens from 1996-2007) in relation to privileges they feel they should receive. "He's just a real jerk", Carla said when asked what the real problem associated with being on the unit was. We had been discussing the long struggle associated with the HIV/AIDS unit at Tutwiler and the slow but steady progress being made. While the women have been accorded many more privileges since the early nineties when Juliette served out her sentence, they are still not allowed into the work release programs that shorten their sentence and they still live segregated from population. Most of the women complained that the ignorance of the warden when it came to dealing with their HIV positive status was such that it felt as if there was a constant battle between the inmates and the administration. When I spoke with Marilyn about the administration, she shook her head almost sympathetically, "It's just the administration itself. It was the whole way of... this is the way it is and this is the way its gonna be. It was just the system embedded in not accepting HIV".

These women see the warden as representative of an institutional system that is inherently irrational based on their outdated views about HIV/AIDS. This brings up interesting questions about the nature of rationality versus irrationality in the prison setting. On the one hand, the inmates view themselves as rational actors dealing with an uneducated and bigoted administration while on the other; the entire concept of the prison is based on supposed rationality and institutional power. In this chapter, I will explore the intersections of power, rational choice, and the institution. How are these power dynamics explored within the prison and how are they negotiated? How does this power structure play out in different social

interactions the women confront inside the walls and at what point does rational choice become institutional control? First, I will lay some theoretical groundwork that lends itself to this discussion.

#### The Institution

In a typically Foucauldian fashion, we see the classification system within U.S. prisons as one which incurs power over a bodily subject while at the same time perpetuating some form of knowledge held in society. In many ways, the power dynamic within the prison mirrors that of the outside world. In his study of New Jersey's maximum security prison, Gresham Sykes draws the parallel between society and prison life:

In reality, of course, the prison wall is far more permeable than it appears, not in terms of escape.... But in terms of the relationship between the prison social system and the larger society in which it rests. The prison is not an autonomous system of power; rather, it is an instrument of the state, shaped by its social environment, and we must keep this simple truth in mind if we are to understand the prison (1958: 8)

This highlights one of the most obvious critiques of the prison system, which is its inability to actually rehabilitate inmates, leading many scholars and activists to the conclusion that the function of the U.S. prison system is to "disappear" certain groups of people so as not to have to deal directly with any unwanted economic burden from said groups. Loic Waquant echoes this idea when he calls the prison a "surrogate ghetto" onto which the double stigma of race and class is projected (2000). The power structure that exists within the prison functions much like it does in regular society with those held captive subject to a knowledge system based on disempowering certain groups. This becomes compounded with the added burden those living with HIV possess.

No inquiry into the nature of the penal system would be complete without first acknowledging Foucault's work on the seventeenth century prisoner as social outcast and the

subsequent reforms that shaped the new paradigms from which the contemporary penal system sprang. In his work, Discipline and Punish (1975), Foucault traces the shift from the body as the vessel for punishment to the soul which responds to discipline and rehabilitation. He states, "The expiation that once rained down on the body must be replaced by a punishment that acts in depth on the heart, the thoughts, the will, the inclination" (Foucault, 1975: 16). The spectacle that was the scaffold was replaced by the cognitive associations of a crime with an appropriate punishment. Judges would no longer judge the crime itself but the *criminality* of the offender; "judgment is also passed on the passions, instincts, anomalies, infirmities, maladjustments..." (Foucault, 1975: 17). In this way, sentences could be lengthened or shortened, probation, medical counseling, and, in the modern day, total confinement can all be instituted in order to correct and claim the body of the social deviant as once again part of the whole. The idea is that to judge someone in consideration of their individual circumstance is to assume that the offender desires for their soul to live by the code of the law. The penal system, in this sense, disciplines an individual in order to alter his soul: "And the sentence that condemns or acquits is not simply a judgment of guilt, a legal decision that lays down punishment; it bears within it an assessment of normality and a technical prescription for a possible normalization" (Foucault, 1975: 20).

### Knowledge and Power

Knowledge in a highly stratified society is produced with an agenda and that agenda is power over the body as means of production or subjugation. The trick is to involve the entire "body politic" in the upholding and normalizing of certain societal rules. By correlating the state to the idea of a body with its associated anatomical parts, we can provide a way to link the individual to society. In a sense, this harkens back to Gramsci's concept of hegemony and the

idea that in order to be able to exercise authority over the lower echelons of society the ruling class must appear valid and natural (1971).

The knowledge that is naturalized contains not just legal structures in place but moral ones as well and this knowledge exerts power over the body because they are bound together by societal and moral obligation. In the new penal system emerging from the eighteenth and nineteenth century, power finds its knowledge system in the concept of a soul. Foucault states that because of this cognitive association, "the soul is the prison of the body" (Foucault,1975: 30). This statement calls to mind the image of Raskolnikov, in Dostoevsky's *Crime and Punishment*, who was driven to confess his crime because he could not escape the guilt he felt over the crime he committed even though he tried to rise above the body politic. He was unconsciously bound up even as he tried to resist.

Power is not simply a product of a class of elites dominating a lower class. Through "the overall effect of its strategic positions" (Foucault, 1975: 26), power is embodied and perpetuated by the lower classes in the name of social order. When a member of a society commits a crime he is actually committing a crime against himself as a part of society and when he does this, he loses his place in the whole. The dominating class is able to justify punishment, and the criminal to agree to guilt because it is for the betterment of the whole society: "the injury that a crime inflicts upon the social body is the disorder that it introduces into it" (Foucault,1975: 92). The "soul" is made up of relations of power and knowledge, and in the case of HIV positive inmates, these women have their souls subjected to discipline based on systems of knowledge they themselves have perpetuated as a part of the body politic. They have internalized these symbols of meaning associated with their disease which circulate throughout society and even as they try to resist these meanings they are caught up and bound within them.

#### Another Brick in the Wall

Discipline, then, becomes the tactic in which the body becomes subjected and useful. It incurs a more subtle act of domination and turns the body into what Foucault calls a "docile body"; it can be exploited economically and dominated politically (Foucault, 1975: 139). In eighteenth century Europe, a "political anatomy" was put into place which defined how to produce docile bodies. Generally, they were used because society had a particular need, for example during epidemics. A political anatomy is essentially a tactic through which bodies can be rendered as useful. Through the use of enclosure and intense classification, a person could be marked as more dangerous in relation to the rest of the inmates. In this way, disease is seen as a form of social disorder for which discipline is its answer. In order to justify discipline, society applies the binaries of madness and reason. Obviously, reason is associated with the rational, the meticulous, and the institution. Deviance would be that which needs to be controlled and whose behavior needs to be normalized as in the case of the "leper" or the "madman", etc. (Foucault, 1965).

Carla, 27, told me she knows that prison saved her life. We had wrapped up our first phone interview and I was surprised at her attitude towards the place that segregated her for three years. Compared to the streets, prison was like living in a boot camp with a bunch of women. She told me that the really positive thing about that experience was the ability to learn to live a "normal" life:

It's (prison) not bad because it gives you structure back in your life and it gave me skills how to live normally because I wasn't living. I was just taking up space but now it taught me how to function. It gave me a routine, a normal routine, caring for yourself, because whenever you are out there using or drinking or whatever, you know, you lose all aspects of reality and with me getting locked up, that gave me structure back in my life and gave me learning skills that helped me learn to live again because it's like you are a baby. You are being taught how to do everything again.

Although Carla is thankful she got the chance to learn to be "normal" again this idea of the state knowing what is considered "normal" is something that other inmates struggle to accept. The power of the prison is the appearance of them *giving* you a choice to live a normal life. From this logic, we see the prison as rational and the inmates as rational or irrational depending on their choice.

The issue that arises here is one that has to do with the reality of the inmate's choice. In many cases, you can either *choose* to behave in the way the system wants, or you will be forced. Lorna Rhodes brings this point up in her book when she writes, "With the power to act on one's own behalf far more available on one side of the bars than the other, choice is the currency that negotiates the resulting dynamic of domination and abjection" (2004: 66). And what happens when this is viewed through the lens of the segregated ward? What happens to the power dynamic when the women view the system as intrinsically irrational? How do the guards/doctors/administration compensate and enforce their power when there is such a large reaction among inmates against it? In the rest of this chapter I will give examples of how those presumed to be in power enforced this in the face of a flawed system and how they kept their control in often unsettling and extreme ways.

#### Medications

Before 2004, for the women on the ward not familiar with their medications, there was no information made available through the prison. With an exhaustive list of antiretrovirals in as many different combinations, it is important for those living with HIV to become familiar to the ways their bodies react to the drugs. Sitting at Marilyn's kitchen table one night she goes over the different treatments she has been on over the last ten years. While I listen to her tick off the names of at least five different drugs, she becomes a bit confused herself and I can imagine it

would be hard for anyone to keep track of. But according to the women I interviewed, most of the women coming on the unit were not even aware of the names or side effects of their drugs nor were they aware of the importance of a strict regimen. This lack of knowledge can be very dangerous to one's health.

When some of the inmates talked to me about getting in the line for medication, they said women would not even know the name of what it was they were supposed to be taking. Some would call the pill out by color or shape and some would not even get in line at all. Additionally, the nurses in charge brought the medicine at different times each day. One former inmate explained that this was dangerous because the women could develop opportunistic infections. One former inmate described how difficult it was to watch women who were perfectly healthy begin to weaken. "Even when women started dying as a result, they were being ignored". This happened not just with the staff but the inmates as well. Juliette told me one day, "There is something wrong when the woman next to you is dying and you aren't even putting up a fuss".

Faced with a group of women who were uneducated about how to care for themselves, nurses and staff were free to give them the bare minimum. Some of the inmates told me the staff had more of a "you get it when we give it to you" type of attitude towards giving out treatment. Marilyn says, "To the medical department it didn't matter. You were a prisoner; you didn't deserve to get your medication." These attitudes also led to most of the women being treated with only one drug. Monotherapy was used in the 70s and 80s when AZTs were the only treatment and generally is not enough treatment for a person. In this case, however, it was more cost effective to just use one medication. In recent years, and after several court cases, this has changed, but for some of the women who lived on the ward at that time, it had lasting effects on their bodies. Earlier, I mentioned Marilyn struggles with health due to her medicine. She has

dropsy, which makes her drag her feet; neuropathy; and lipid masses under her skin due to a bad treatment regimen.

This example offers insight in to what Lorna Rhodes refers to as "the choice to be good" (2004). Although the women are expected to be in control of themselves and the medications that go into their bodies, little in the system offers that opportunity. Without any counseling from the medical staff, uneven treatment times, and a small variety of medications to choose from, the "choices" they make in regards to their health can only be taken so far. They are expected to "choose" whether to take medicine or not and expected to wait in the line for their medicine and ask for it by name, but doing what you are expected to do is not really much of a choice. The medications line, then, becomes the symbol of the internalization of the control exercised on the inmate through the logic of their "choice to be good."

## The Doctor Patient Relationship

In looking at the doctor patient relationship we often see the balance of power skewed in the favor of the doctor. This is because we believe our doctors to be experts in care giving and because they also assert this authority through their class and educational status. In many ways, we trust them to make decisions about our bodies that we believe we are not knowledgeable enough to make. For the women in the medication line, the "control" they should have had over what went into their bodies was not in their hands. They were at a larger disadvantage because they were faced with a staff that ignored them. During her sentence, 1997-2000, Juliette became more and more disillusioned with the way the medical staff treated the women on the unit:

They just wouldn't do anything for you, they just ignored you. They would say we'll see if it gets better in a day or two but in a day or two you are dead. Or they would say we just don't have the staff to take you right now. And then by the women having no kind of cohesiveness they wouldn't put up a ruckus to get the person out. Because they would just listen to whatever they would tell them.

In his 1988 book *The Illness Narratives*, Arthur Kleinman describes "the double bind" that patients experience in relation to their doctors. In this relationship, a doctor expects a patient to be able to actively participate in improving their health in the outpatient phase, but if something happens and they become sick they are expected to take the blame for this and become submissive to any treatment the doctor wants to make (171). This relationship can create feelings of confusion and guilt in a person and reinforces the power dynamic. The women on the medical unit are expected to take responsibility for becoming infected and also for landing in prison. Even though they are told to "take control of their lives" they are expected to submit to the control of the medical staff.

Carla spent the majority of her time on the unit trying to get better. The shock and disbelief she felt upon hearing she was HIV positive were quickly replaced by feelings of despair and powerlessness. She was so sick when she went into prison she felt was near death. The prison doctor who saw her told her she would not live past the next year. Broken and disempowered by the doctor's words, Carla made little effort to change the direction of her life. She did not go to the trade school or get her GED or enroll in counseling because she was told she had no time left. In this instance we see the double bind put on Carla as she was asked to take responsibility for her disease, yet take the doctor at her word, and resign herself to death. Eventually, because of the guards and the other inmates who protested the doctor's action, the doctor was asked to resign for making this comment. This unfortunate situation happened often when it came to treatment of women who have already lost the right to equal privileges in a portion of society's eyes. This type of relationship is indicative of not only the abuse of power felt in prison, but the overcompensation by medical staff to enforce the system of power in place even though they are unaware of how to treat the women on the unit. Juliette told me that in 1994

the nurse who told her she was HIV positive said that she needed to inform herself; "I needed to learn everything I could about HIV because this was a disease that doctors may not even know how to treat me, that I needed to learn everything I can so that I can take care of myself". For those with HIV, knowledge is power and engaging with members of staff with minimal knowledge became another struggle set against the backdrop of choice and rationality.

## Education, Programs, and Prison Staff

Most of the interaction inmates had with those "in charge" were with the correctional officers or "guards" as they call them. The guards, many times, are in a similar socioeconomic class and are of the same racial identity (African American). Some of the officers also suffer from similar problems, such as addiction, to the inmates. Before Juliette went to prison, she lived with her husband and children in the U.S. Virgin Islands. She was a correctional officer there and it was there she befriended another officer who introduced her to the drug that would eventually land her in prison three years later. This social relationship to the staff sometimes made the power dynamics all the more tense as attempts to assert authority were made by the guards. Three of the inmates serving time together told me that one officer was "always trying to stir the pot" between the inmates and get them to tell on each other so that she could catch them.

Marilyn told me that she observed a hierarchy between the guards and the medical staff. The guard for their dorm was removed for choking a nurse after she was "jaw-jacking" or talking down to her; "she choked the nurse because she was getting on her nerves. And she wasn't an outlaw but she was from the projects and she had it hard too you know?"

The relationship between inmates and guards is a slippery slope in which the will is constantly being exerted on both sides. This relationship does not exist in a vacuum however, and as stated earlier in this chapter it is closely linked with the prison itself as an institutional

power. Many times, the guards were the ones caught in the middle and are made to enforce rules they did not always necessarily agree with. One inmate called them "high paid babysitters" and explained that in her experience they were always helpful and understanding. When met with resistance from inmates, the guards were essentially the ones that were responsible for keeping inmates in line by insisting that they "choose" to conform. If inmates did not conform the staff had to use some type of force in order for them to submit.

One of the biggest issues in terms of power dynamics between inmates and guards had to do with knowledge. The inmates who served their time in the late nineties talked about how difficult it was with guards because of their lack of knowledge of the prison system. They perpetuated the stereotypes associated with HIV/AIDS because they were not educated about the disease or about how to deal with the women. Because of this lack of knowledge, "they (guards) tried to encourage the prison population to feel that way. You had the prison population that responded in that negative way because the environment motivated and put that in your thinking". All of the women I spoke with told me that education is the most important thing when dealing with your diagnosis because denial can be so strong at this point. If they are not educated then they become disempowered and ambivalent. It is at the intersection of power and knowledge that the prison system holds much of its power. By denying access to programs, counseling, and outside information, they are able to keep knowledge and therefore empowerment to a minimum.

According to the former inmates who served their time before 2004, there was minimal counseling available to them when they first came on the ward. Some of them became disillusioned because of this. Although there were some programs, Alcoholics Anonymous and Narcotics Anonymous for example, that came onto the ward, many women felt a sense of helplessness because of not knowing how to deal with their disease. Here, the staff would insist

that the inmate make the effort to participate although it was not required. This is how they can gain their "personal" power. Lorna Rhodes says of inmates in maximum security who chose to take advantage of self-help courses:

The inmate was a blank slate, on which a dysfunctional self was inscribed. *And* in the mess created by that self, he can chose to look for his true self, his best self. The true self can be found only if he can see himself as not merely inscribed but as having chosen (2004: 74).

It was either this or simple warehousing of inmates, "you live until you go home". The question here becomes what exactly is it that you are able to learn from these programs and how much personal power does an inmate actually gain from the small amount of programs available?

One of the first things Juliette and Marilyn tried to do for the ward was form a petition to get computers to use so that they could learn about their disease. Due to the lack of programs and lack of knowledge of the staff they had been forced to look elsewhere. There were some non-profits and activist groups that came and gave them literature to read, but Marilyn said they wanted to be able to search on their own. It was important to them to find literature for themselves and to connect to women and groups who were infected and affected with HIV/AIDS. One inmate told me,

Doctors can't never tell you this is your disease, you're gonna have to tell the doctor. And the more information you know, the more ability you're gonna have to take care of yourself and live longer.

They were able to get a trailer with a few computers in it out behind their building. However, this trailer had to be on the terms of the prison. Much like Foucault argues, the body of the prisoner was controlled tightly by the power of discipline. Marilyn explains that, in the beginning, use of the trailer came with many conditions,

They were trying to keep us satisfied but it didn't do any good. We had to have an officer watch us.... Why do we have this trailer and not use it? They tried to make us look good

by what they were trying to do for us but they weren't doing anything. We were still bored with nothing to do.

What the women viewed online was controlled and any information they wanted had to be closely mediated by the guards. Although they were given a choice to become more knowledgeable the guards only "empowered them to live to the bare minimum" as one of the inmates said.

Before 2004, the inmates observed that the guards knew very little about HIV. Carla, who served her sentence after 2004, said the guards were very helpful and knowledgeable about HIV. This is obviously very encouraging because it may mean that the level of knowledge the inmates are able to attain is much higher than when Juliette and Marilyn served their sentences. They talked about having to educate the guards because they knew so little and because they knew so little, they became intimidated if the inmates knew more.

## "Knowing More Than They Do"

Juliette described an experience she had when she came back to teach in the prison after she had been released. She explained to me that her goal was to give the inmates the tools to find information on their own. She gave them names of organizations dedicated to supplying information about medication, eating right, staying healthy, etc. This was all literature she had received while in prison. Most came through the mail and was generally approved at the time she had been incarcerated. The inmates began to send for information outside of the prison just as Juliette had done. Once this began to happen, the staff came to Juliette and asked her to leave. She told me their reasoning was that they were ordering information they were not allowed, but Juliette says she knows the real reason was because they had begun to ask for additional services and privileges based on things they were reading. For example, through literature they received they began to realize that the American Disabilities Act protected them from the discriminatory

policies on the ward. They now began to ask for access to trade school and GED programs and staff could no longer find an argument they could win.

They (the staff) could not handle it and as a result the inmates were more knowledgeable than they were and they didn't want that. They wanted to educate you just enough that I can keep you under me. The staff and the people who were over prison initiative and educating. They wanted to educate to a minimum but to educate you where you were as knowledgeable as me or you could go on your own and find out information that I didn't know. NO. And they wiped me out of there.

Juliette was no stranger to being suppressed by the institutional power of the prison. While she was an inmate, she began correspondence with a number of different media outlets. Without asking permission from the warden, she set up interviews and sent mail out in order to call attention to what life was like for the women on the ward. She was hardly the only one doing this at the time. Lawsuits were filed against the prison as early as 1986 and the men's prison had been spotlighted as well. When the warden questioned her one afternoon about NBC's request to come and interview her, she was not very cooperative. When the warden asked to see her correspondence she refused. Juliette believes that because of this the warden illegally disclosed her HIV status to her children during their Christmas visit. She said walking into her visitation was like walking into a funeral. And the hardest part was seeing the faces of her children, who had come with a woman from Department of Human Resources, in tears and disbelief. The warden had taken her choice as to how and when to tell her children and attempted to disempower her and her family. Juliette said,

She deliberately did it because my family was empowered, DHR and I had this fantastic relationship and she felt like I should be punished more than I was being punished. I just took advantage of what was available to me and used it to the best of my ability.

These examples highlight the argument that the prison creates and perpetuates a knowledge system in which certain populations are kept disempowered even as they attempt to create their

own knowledge system. It is an advantage for the hegemonic powers to perpetuate stigma by blocking knowledge and here we see how they circumvent women's attempts in order to assert control. Although guards were charged with carrying out the state's methods of control, we can see that they are not always successful and the strategy of giving a prisoner a choice to use their will to enact a positive change is something that is still closely regulated and restricted. The inmates began to react against a system they felt was irrational and uneducated and in some instances had their efforts blocked. In the next chapter I will look at some examples of how the women reacted against this power dynamic in creative and thoughtful ways. By doing this they were afforded small victories and privileges as well as a sense of their own agency.

### 6. I DON'T CARE WHAT YOU THINK ABOUT ME, GIVE ME SERVICES!

One of the more surprising things I found during my research was how much agency these women had. After reading newspaper articles, court briefs, and other literature relevant to the situation of HIV segregation in prisons in the south, I believed I would find women who spent most of the interview telling me how they had been wronged and how desperate the conditions were on the unit. This idea, however, is a product of an image we hold in our minds of how we think the prison and the inmates should act. When I asked Tasha about how women on the unit empowered themselves, she admitted that some women reacted in what she perceived as a negative way.

The others kept their power through getting in more trouble. That's how they managed. Raising hell, anything to keep from hearing the sounds in their minds, or keep from feeling whatever it was that they were feeling. Fighting each other, it was always something. I just never connected to that.

What I discovered more often than not in the women I interviewed was that they focused on the positive aspects of their experience and were very thoughtful about the situation they found themselves in. Left with very little in the way of a benevolent prison system, women activated their agency by reacting against the power dynamic in ways that reflected a gap in the way the prison was run.

There seems to be a "before" and "after" picture the inmates paint for me about life on the unit. When they talk about "before" they mostly refer to pre-2004. "2004 is when we made history and they gave us our dorm, before that we could only go to drug classes and back" one former inmate says. Before 2004 it was an up and down battle for equal treatment and for the right to education. After 2004, women were put on the hall and only denied access to some work release programs and still segregated on the hall. The only former inmate I interviewed who

served her time after 2004 echoes the sentiment that medical staff, guards, and administration understood and were helpful, and respectful on the unit. Carla tells me, "You know they talk to you. They (the guards) treated you like a human being. We even had one guard sit down and eat with us. I didn't feel it was bad". The other inmates observed a change taking place within the dorm while they served their time as one in which you saw a "totally new type of inmate".

Women saw their fellow inmates dying, they saw people being ignored and for awhile they went along with it. Eventually they began to take action and employed strategies to enact change not only within them but in the social space they occupied. They say this new wave was a result of changes in policy, living conditions, and a level of mutual respect between staff and inmates. In our interviews, we talked about several different examples of the way the women use the system to empower themselves on their own terms and the types of things in which they find strength in.

In this chapter I will describe the strategies these women utilized to hold on to their personal will and empower themselves to react against the power dynamic of the prison in positive ways that ultimately, in the cases of the women in my study, helped them to stay healthy on the "outside". In other words, how did they stay motivated and empowered to stay healthy and positive given their circumstances?

### Acceptance from the Base

After their initial diagnosis, many of the women struggled with how to disclose their status to their loved ones. Erving Goffman refers to these people as "intimates" or those who have a personal knowledge of the stigma-bearing person previously and who are more prone either to sympathy or an extreme of emotional discomfort. He also adds that intimates will play a special role in that person's management of their stigma based on the reaction they have to it (1963:51-55). Juliette made it clear to me in our first interview that her initial motivation to "live

with HIV" came from the acceptance of her family. When she finally told her husband she was surprised at his reaction because he was supportive and understanding. She told me after she got his acceptance she found the courage to call other family members and with each phone call some of the weight she felt keeping her status hidden began to lighten. She says, "Him accepting me and talking to me was like giving me permission to live with HIV and everyone I called just loved me and I was able to focus on recovery (from addiction)". Parker and Aggleton describe the family unit as the basis for care and support among diagnosis and stress that this relationship is important because without this support an individual can feel a "secondary stigmatization" that can contribute to further isolation of the individual (2002:8). For those with family to call, this became an important step. They describe the emotions of empowerment each time they disclosed their status to a loved one as if just speaking the words gave them some more control over their disease. From then on, they could work on managing their health. However, many women in the prison system have had their children permanently or temporarily taken away and many more are victims of physical and sexual abuse sometimes from family members. According to a 1999 Bureau of Justice Report, 4 in 10 female inmates reported some type of abuse before imprisonment; fifty percent of these abuses were experienced at the hands of an intimate compared to three percent of men (Greenfield and Snell, 1999: 5-6). Based on this data and from the interviews with women, I found that their base of support came from the people they were surrounded by at the time. While many of them lacked the support of any real family on the "outside", they were able to find solidarity with each other.

### Petitions, Plays, and Programs

Tasha was very young when she contracted HIV. At twelve years old she was not even a teenager. She never knew anyone she could share with until she became incarcerated and the

solidarity that was fostered between the women was something they all agree gave them motivation and hope. She told me,

I had totally gave up. I just wanted to die, but people (in the prison) talked to me even when I didn't want to hear it. But I heard it anyway and I didn't think I was hearing it but I was and people just gave me the strength and hope that I can still live.

So on the unit, women became advocates for each other and began to form cohesiveness between them that became a community. Within this community, there were the inmates themselves, sympathetic others such as guards and activists, and non-profits that brought in programs.

Together they brought in educational materials, programs, and formed class action lawsuits to fight for equal rights and by doing so, retained agency.

Marilyn's experience in Receiving left her frustrated and helpless. "I was so upset coming on the unit", she said, "so me and a few others wrote a play". Instead of responding in a negative way to the way she was treated, she made a choice to do something positive and speak against it without breaking any rules or warranting any sort of disciplinary action from the guards. In the play, Marilyn, Juliette, Tasha, and two other women reenacted the incident in Receiving for the other women on the unit. Afterwards, the women were able to talk about similar experiences they had and how they felt about them. Much like Boale's Theater of the Oppressed, the women created a theatrical space in which they could inject themselves into a dialogue with those people they saw as oppressors. Boale argues that every human being possesses the capacity to act in their everyday relationships with others. To be conscious of this ability to be both actor and object in a situation, a person is in a better position to actively participate and retain agency. By using what he calls, "theatrical language", an individual can enter in to a dialogic relationship with the oppressor and learn to react to situations I order to resist and change that oppression (www.theateroftheopressed.org). By reenacting this situation

for the women on the unit, women learned how to act when dealing with the uneven power dynamics they faced as HIV positive women in prison.

In the late 1990's the women living on the medical unit began to petition for access to services. The ACLU had already begun a class action lawsuit in 1987 based on Section 504 of the Rehabilitation Act of 1973 in which they contested poor medical care, no access to prison programs, and segregation for both the men and women's prison in Alabama. Of course, according to Juliette, Marilyn, and Tasha, the early 1990s had seen little actual change in the prison due to the fact that the courts continued to rule against them (Russell, 2000: 26). Marilyn said;

The inmates in 87 started the lawsuit. All the old inmates who were coming back thought nothing would ever happen so they quit until a couple of friends, we just got tired of sitting around and it was time for something to happen. (Donna) got the right papers to get things moving and we started a petition"

Taking their cue from the men's prison, which was beginning to get access to some services, the women all signed a petition to receive access to programs and educational materials. The women pre-2004 talked about how angry the warden would get with them for reacting against the institution. When I asked Juliette if she ever got in trouble for spearheading many of the educational advocacy campaigns against the prison she told me that she never gave them any reason to: "I kept to myself, I wasn't gonna give them any reason to come after me".

As noted in the previous chapter, those in charge found other ways to assert their authority when the women on the unit attempted to create a space for their empowerment such as the warden disclosing Juliette's HIV positive status to her children. Another inmate whom the women described as a sort of leader among them, Donna, was thrown into solitary for having a relationship with a woman from population, and therefore supposedly endangering others.

Marilyn described one instance in which Donna was punished with what she believed was an ulterior motive:

He (the warden) didn't like her because he knew she was smart and made him look bad. So he knew Donna was "a boy" and he didn't like the way she would do things. But the only thing he could do was lock her up. They would lock us up in the mental health ward.

Marilyn said that later, after the women continued to be vocal about equal treatment, the warden finally went to the commissioner and the Department of Corrections and expressed worry that "we will have to pay every one of them off" and after a meeting they were able to participate in many of the programs offered in population, such as trade school.

### The Role of the Non-profit Organization

When programs finally began to become available to the women on the unit, most took advantage. By connecting with people on the outside who were allies, they were able to find some of their own power. Non-profits, such a Southern Center for Human Rights and the ACLU brought information on the unit and the women were able to learn about HIV on their own terms. Other programs such as Alcoholics Anonymous and Narcotics Anonymous gave them additional support in dealing with whatever recovery was necessary for them.

Many of the inmates repeated the theme of "choice" in relation to participation in programs and the importance of individual action. The agency of the individual would ultimately connect her with a large group network and empower her with knowledge she was not able to find readily on the unit. Tasha told me with regards to the programs available through non-profit organizations that "you could let them walk out the door or you could say work this program with me". So she worked the programs and was able to find a job and housing upon release. Juliette and some of the other inmates got some of their writings published in a compilation of poetry by participating in a writing program a woman from a non-profit organizations came on to

conduct. Beyond being challenged by the writing process, Juliette told me "the most I got out of it was just being with her and you forgot you were in prison".

Two of the women I interviewed ended up coming back to the prison after they were released to teach classes on the unit. Carla is planning on going back and teaching because she got her certificate to teach HIV classes while she was still in prison. Because many of the women are still in touch with women on the inside, they are drawn to come back and give of their time to educate which they all see to be an invaluable part of maintaining your empowerment. Juliette told me how compelled she was to go back and teach and she told me that the tearful reactions she got from women when she arrived only solidified her resolve to educate.

### Advocacy

Some of the women emerged as leaders while they were on the unit. They were involved in many of the programs offered, they were outspoken in regards to equal rights, and they made it a point to get everyone involved. All of the women in my study were exceptional in this way. They all worked hard to maintain agency in a positive way and react against a system that did not work for them. Some of the prisoners Lorna Rhodes describes in her book react against the power dynamic in extreme ways, such as throwing feces, as a way to literally respond to the way they are treated; "you treat me like shit, I throw that shit on you" (2004: 45). While this is a more sensational response to the issue of control within the prison, it still rejects the idea of the prison as an instrument of control of the body and points to the inherent contradictions in the prison system that assumes a body will become a "docile" one. Women on the unit rejected the control of the system in a less literal and more productive way through their advocacy both inside and outside the walls. Women like Juliette and Donna became spokeswomen for the unit and increased awareness of the conditions of the ward through their advocacy.

Juliette and I talked a lot about her advocacy both inside and outside the prison and how important that was to her empowerment. She told me that as soon as she processed the reality of her segregation,

My next thing was to look for every opportunity I could to empower because that's in my soul. Anything and everything in HIV... the officers, anyone I came in contact with. You must be educated, you must be empowered and that's the only thing I knew that was before me. I couldn't participate in that; I had to maintain my empowerment.

She also began to advocate on a national level. After the prison responded to their request for more information by giving them a trailer, she began corresponding with organizations and media. She sent letters, did interviews, wrote articles, and "flooded the unit with the mail". She responded to the lack of local advocacy and education in the prison by creating it herself. In this way, she actively participated in changing the system by bringing awareness and therefore concern and policy change to the issue.

The women all talk about the importance of using their agency to demand equal treatment. Instead of passively accepting their place within the system, the women actively engage in producing a new system within the one they find themselves. Their power comes from enforcing the right to treatment. One inmate says, "what if they don't give me treatment? Oh well you can fight even harder, that's gonna be a good thing. Do you know how powerful it is for them *not* to give you treatment?" This elevates the level at which they can enforce agency because it establishes an inconsistency in the policy of the prison and therefore a gap through which the women can advocate.

Neoinstitutionalist theory suggests that social institutions survive to some degree based on their ability to provide social rules and systems which are maintained due to cognitive conceptions of rules and norms. Individuals act accordingly within an institution because they

can conceive no other alternative to behavior other than what has been legitimated by the institution through the repetition of those social actions by individuals (Meyer, 1977). Paul Colomy suggests that although this theory does a good job in describing the ways in which institutions survive in a society made up of many institutions, it pays little attention to the importance of agency in institutional change. He suggests that by looking at smaller factors, such as the actors or organizations that are actively participating in institutional change, we are able to see the importance of agency at work within large institutional systems (1998: 294). In other words, individual agency plays an important role in changing the ethos of an institution and people are not all just passive actors within the system. The women in the prison offer an example of this principle at work. By organizing petitions, spreading knowledge, and advocating where they could, they were able to have a strong hand not just in how they were affected but how others who would become part of that institution were affected. In challenging the institution itself as one that had inconsistencies they were able to create a change not just by reform and policy but by questioning the very existence of the system of segregation and exclusion itself.

### The Church as a Way to Power

When speaking of this abstract idea of a "before" and "after" image of the HIV positive female inmate in segregation, I spoke first about the instant that a person begins to negotiate their identity after learning of their diagnosis. This process can be a slow and frustrating one for the women on the unit because many are struggling for the first time with knowledge of their disease and many more struggle with abuse, addiction, or complacency within a system that continues to hold populations captive under the law. The women all began to draw power from each and the bonds they made with inmates, guards, and other prison staff which in turn lead to empowerment

and action. When I asked the women how they were able to stay empowered they all mentioned sympathetic others, participation in programs, advocacy, and education. But they also almost unanimously mentioned God as a higher power in their life that they drew enormous amounts of strength from. This reliance on God was interesting because it speaks to the major role that church service organizations play in the prison and the community, especially among African American populations, and the prison population as a relatively controlled population to minister to.

"If you keep your faith all he can do is open doors for you. And all I can do now is praise God for what he has done for me", Marilyn told me the first time we met. She was living in an apartment she found through AIDS Alabama that was attached to a church. Carla also found housing through a Christian organization called Lighthouse Counseling Center that offered drug rehab, counseling, and help with job search and housing. This, in essence, is what a pre-release program paid for by the state Department of Corrections or Parole is supposed to do. In many cases, the budget, especially in a woman's prison does not allow for programs like this so other independently funded programs step in. The women in my study almost always mentioned some type of program with a religious thrust. The question becomes why these Christian organizations as opposed to other, non-secular ones are so involved in prison work and ministry. And what is it about this ministry that becomes so attractive to the women in the prison?

I notice that Juliette has at least three *Bibles* in the passenger seat of her car as I slide in beside her on the way to dinner. Her home also has crosses, framed *Bible* verses, and inspirational music playing most times I come to visit. The church has always been a part of her life and although she was required to participate in a church related rehabilitation after her first incarceration, she never felt she was being coerced or proselytized to. This may lie in the fact

that the African American church stands as "a bulwark in the Black community" (Barnes, 2005: 967) and extends its influence to politics, economy, and culture. In their study on the Black church as a "semi- involuntary institution", Matthew and Larry Hunt historically place the church within the context of segregation in the south and the sense of community the church fostered in the face of racial segregation (2000). This work suggests that a more modern interpretation of the role of the Black church may call for service in those areas in which Black people continued to face segregation and racism. Obviously, the prison is an ideal context for which to further this message of community because a majority of those in prison are African American.

Carla talked a lot about a woman from the church who she called "mama". This woman had a major impact on her life and gave her a message she was able to use to empower herself:

Emily: That power (from the church) you get is from motivating yourself to do better.. Carla: Exactly. And wanting more out of life than where I come from. But I don't forget where I come from and I don't forget where I can go back to if I fall weak again and I remind myself of that everyday. I am far from biggety about it because I can't take credit for any of this. I give my credit to my higher power.

"Mama" has been an outspoken advocate for the women in this prison for many years, it seems.

Both the women in the prison and those working in the non-profits speak very highly of her.

Beyond her advocacy on behalf of the women, she offered an example of the community they could be a part of. This community has historical roots in the fight for equality and so translates well for those who feel they are oppressed.

Another draw to the church could be its function as a place of status and respectability. Hunt argues, "the Black church is a key institution in modern, urban America that aids in differentiating those with 'decent' from those with 'street' value-orientations" (2000: 590). While in the process of recovery, the inmates may be drawn to the idea of becoming

"respectable" citizens. This point, I believe, could be useful in accounting for the large number of women (and men) in prisons who rely on faith and the church as a way to empowerment.

#### Conclusion

There are two ways you can retain your power within the prison setting. You can act out and against the rules, or you can "obey". Within this construct there can be a little room for negotiation and the women in my study situate themselves somewhere in between the two extremes. In some ways they are reacting against rules and a power dynamic they believe to be irrational and unfair. In another, they are going about their business and causing a "ruckus" in more subversive, thoughtful, and productive ways. In his recent book on Tutwiler's brother prison, Limestone Prison in Alabama, Benjamin Fleury-Steiner places their situation within the context of race, health policy, and the warehousing of marginal populations (2008). He correctly points out the very cruel and negative influences the system has on those imprisoned in HIV wards in Alabama. However, the women I interviewed surprised me with how well adjusted they were to being confined. This is not to say that they were complacent in the blatant abuse of human rights they found themselves a part of, but it seemed as if they tried to focus on the more positive aspects of incarceration. Instead of dwelling on their plight and becoming victims they were reflexive and found ways to react against the power structure they viewed as irrational.

In Bosworth's 1999 study of women's prisons in England she veers from the neofunctionalist, neoinstitutionalist approach and situates the women in the prison around the concepts of agency and resistance. "For her, women's abilities to negotiate power in prison are shaped by the ways they construct, through the intersection of race, class, ethnicity, and sexuality, their identities (41)". The prison then becomes a symbolic stage on which the inmates are constantly engaged in negotiations of power. The incredible amount of agency the women I

interviewed were able to activate as a result played a large part in the changes they began to see on the unit after 2004. The prison presupposes a loss of agency of an individual through the control of discipline. Especially for women, the prison can be a site that reflects gender relations in society. In these examples, the women highlighted the inconsistencies of the very fundamentals the institution relies on and actively engaged in the politics of resistance and femininity through their own identity construction.

When looking at the ways women have negotiated power within the system, there are a few themes that emerge. First, by identifying with the other HIV positive women on the unit, a type of community is created. This solidarity within the unit allows the women to organize for rights and find a sense of purpose in prison. Second, they resist the depersonalization of the system by educating themselves through independent research and one on one counseling programs. Finally, they rely on a higher power as a way to cope and gain respectability. Overall, the women in the study spend a lot of time being reflexive and thoughtful about their individual situations. This trend has emerged in other studies focusing on female inmates and has been a focal point when thinking about a gender responsive prison. In the next chapter, I will explore some of the unique experiences women, and particularly HIV positive women, have in adapting to the prison, in dealing with social relationships, and what characterizes the female inmate today.

#### 7. WOMEN IN PRISON AND FEMINIST INFLUENCED POLICY

The female inmate continues to be treated and analyzed in ways that differ from men. Whether because of the smaller numbers of women being incarcerated, blanketed assumptions of their psychology, or perceptions based on societal gender norms, policy and punishment of women inevitably reflects these assumptions. The Prison Industrial Complex opened the proverbial floodgates as government officials competed with each other to see who could be "tougher on crime". As a result, there was an incarceration boom in the U.S. that could almost not build prisons fast enough to be filled. Women became an unwitting recipient of the brunt of much of the policy enacted at this time. As women's rates of incarceration began to steeply rise, the scholarly literature, research, and policy has compensated by exploring many aspects of the experience of a woman in prison.

Between 1990 and 2000, the rate of incarceration for women rose by 125 percent according to the 2001 Bureau of Justice Statistics (Kruttschnitt and Gartner, 2003: 2). As with men, women from a lower socioeconomic stratum and African American women were disproportionately affected with 212 per 100,000 African American women imprisoned in 1999. Additionally, the types of crime associated with imprisonment was generally non-violent and drug related- 34% in 1999 (Kruttscnitt and Gartner, 2003: 7). With the passage of the Sentencing Reform Act of 1984, every person was given the same sentence for the same crime. This meant that women who had children or had a first offense did not receive any special consideration compared to anyone else convicted of the same crime. These set of circumstances combined to create an extremely unfavorable environment for many women.

Numerous scholarly articles dealt with teasing out some of the reasons that would account for this large rise in the numbers of African American women in prison. Beth Richie

argued that gender specific roles in our society have produced what she refers to as, "gender entrapment". She defines this as

A socially constructed process whereby African American women who are vulnerable to women's violence in their intimate relationships are penalized for behaviors they engage in even when the behaviors are logical extensions of their racialized gender identities, their culturally expected gender roles, and the violence in their intimate relationships (1996: 4).

Many female inmates have history of abuse as I pointed out in the previous chapter and also find themselves as the primary caregiver in the family unit. Due to their economic circumstances, many turn to drugs and other non-violent offenses for either money or escape and end up cycling in and out of a prison system that criminalizes their efforts to survive. Bound up within this dialogue is the epidemic of HIV within the same population. This is reflected in the statistics of HIV positive women in the prison system; 3.5 percent of women in prison have HIV compared to 2.5 percent of men (Zaitzow, 2001: 673). This picture of the HIV positive female inmate can be disheartening as Zaitzow argues, "Female criminal behavior appears to be the product of continuing social problems- the impact of physical and emotional abuse and extreme disadvantage, exacerbated by economic problems as well as drug and alcohol abuse" (2001: 675). However dire this situation may be, and it is, it is important not to treat these women as mere victims of a patriarchal system. By doing so, we deny them agency and assign lower expectations in terms of ability to affect changes in their lives. Ritchie (1996) addresses this dialectic between a woman as a victim of social forces, while at the same time, a survivor. The goal of this chapter is to first look very briefly at the circumstances of the women in my study in order to situate them within their personal experiences that lead to their incarceration, then to discuss how they adapt to the prison and to segregation because of their gender and HIV status, and finally to describe the effects their imprisonment and status have had on their experiences

post release. Finally, I will discuss recent feminist scholarship on the gendered nature of control as it relates to what is has been called the "gender-responsive" prison.

#### Circumstances of Women in Prison

The situations that the women I researched found themselves in did not differ very much in terms of the offense and how it subsequently led to their infection. I have chosen not to single out any of the women when I talk about their offenses or personal histories because I did not want to either romanticize or stigmatize them further. I only discuss what characterizes them here because it is important, I think, to understand what it was they were dealing with before they entered the prison and how this may affect both news of disclosure, feelings they may have had about themselves, and their recovery. All of the women with whom I spoke with struggled with addiction for one reason or another. Most cited drugs as an escape from the reality of their lives, whether it was abuse, abandonment, or just mental health issues. The women also talked about their sexual dependence on men in order to fulfill their addiction and say that it was most likely sex with their male partner that led to their infection. Only one woman cited rape as the reason for hers.

I asked Juliette one day why protection was never used when the African American community knew they were at high risk for infection. Beyond the fact that addiction can cloud judgment, she told me that, culturally, she felt Black women were not sexually empowered. She told me that in sexual relationships women allowed men to have the power and many men choose not to wear a condom. While this is certainly a point that can be contested, she brought up an interesting point about the denial of the disease that exists in members of the Black community and said, "it has been abandoned in the African American community just like it has abandoned everything else. Perhaps the lack of dialogue about transmission and misperception

that it was only associated with homosexuality, therefore, "straight" men could not get it regardless of sexual behavior and the heavy social stigma all led to this denial.

### Taking Time to Adjust

The similarities of the women I interviewed stop beyond the basic social and economical circumstances of their imprisonment and infection. Studies such as Zingraff and Zingraff in 1980 focused on women adapting to prison life based on their varied biographies and identities while moving away from viewing female inmates as a homogenous set of women who would respond in predictable ways based on their "femininity". This line of thought is especially useful when talking about segregation of HIV inmates because it assumes that the women on the ward would have identical needs to each other. The implication that all the women would accept knowledge of their status in the same way and react to a controlling prison environment is irrational based on the fact that women on the unit were imprisoned for various crimes, had different levels of health, and potentially had other mental and physical problems. Thus, looking at the way women adjust to prison yields varied results.

Three of the women in my study illustrate the differences in coping mechanisms depending on level of health, personal history, etc. After being treated so badly in Receiving, Marilyn told me she acted out: "It wasn't ever nothing physical, just little things here and there. She (the guard) would always catch us smoking but I would just get back up in her face; she wasn't gonna talk to me no way". Marilyn initially responded to her environment negatively after having being kept locked away for so long. She continued to be vocal but redirected that aggression into actively participating in petition writing and advocacy. Juliette stayed "straight" and adapted by continuing her advocacy and participating in programs: "You didn't wanna stare at the walls. You have a mind... I had my mind, I had to utilize that in some form so I did

everything there was to do, no matter how minute". Carla stayed depressed because her level of health was so low. She just "waited to die" and never really got out of her bed. Adjustment can be a long and difficult process and that will differ for each woman depending on her special set of characteristics.

Some studies such as Heffernan's (1972) exploration of Occoquan prison in Virginia suggest that there is an element of agency that exists in the coping mechanisms used by women that does not appear in the studies of men's prisons. For example, early studies of men's prisons focus on a functionalist perspective of the institution with men creating another social space in which various roles that existed in larger society were filled. For women, there was less focus on the group mindset and more introspective work. Carla echoes this when she tells me about the differences she believes she sees between male and female inmates. She told me that they had more programs in men's prison and she believed the reason was because they:

...were more powerful and have the ability to take more control over the prison so they would provide them more to keep them in a calmer state. Women aren't as powerful as men. They don't stick together enough to retaliate on the level that men will.

Much like I found in my research, these studies link women to a more introspective and active inmate. All of the women in my research took full advantage of the programs available to them and seemed to respond best to those geared towards a one-on-one type of exchange. In a 1994 survey of women's prisons noted that, "with regard to levels of participation, women scored higher than men in many respects" (Krutscnitt and Gartner, 2003: 45). They used these programs as a way to adjust to and cope with the monotony of prison life as well as in order, they told me, to gain something from their experience.

I never carried myself, they respected me because I wouldn't give you an opportunity, look, I was a woman when I came in here and I am going out a better woman. I wasn't in their faces for nothing. I didn't ask for anything. I was empowered within myself. I didn't

need them to rehabilitate me because I used whatever was available to rehabilitate myself. I woke up; I had my day already planned. (Juliette)

### Another former inmate said:

It is as difficult or as easy as you make it. Because you can use the resources they give you there either for you or against you. It all depends on how strong your will is. For me, my will is strong because I didn't wanna go back to my old way of life. (Carla)

While they were able to find agency in their participation in programs and advocacy they still experienced some difficulty when adjusting to prison life. Two issues that the women I interviewed had trouble with were their health and being separated from their children.

#### Health in Prison

Medical services for women in prison have always been basic at best. Even though women have a higher incidence of HIV infection and tend to (in general) use medical services more than their male counterparts the budget is much smaller based on the larger percentage of men in prison. Studies have shown that women become infected as a result of things such as drug use, sex for drugs and money, sexual abuse, poverty, and "other gender-specific conditions of their lives that make them more prone to HIV infection" (DeGroot, Leibel, and Zierler 1998 in Zaitzow, 2001: 676). All of the women in my study became infected outside of prison and found out about their HIV status in Receiving. A mandatory test must be taken while the inmate is in Receiving, as well as a physical to test general health. Some of the women come in already very sick and have contracted opportunistic infections due to their HIV status. Because of the large numbers of women coming through receiving each day, women who are HIV positive and have not been tested may sit for weeks alongside other women who may complicate her infection. Others, like Tasha and Juliette, were asymptomatic and relatively healthy.

One of the justifications for segregating the women on the unit is because they have easy access to medical services. But, as noted earlier, only a small amount of resources are allocated for the women's prisons. In the case of the prison I worked in, the inmates told me that they were sometimes treated with similar medications so that they could be cost-effective. Tasha told me, "the way the drugs work is with the chemistry of your body. Sometimes you have to go through a lot to see what works and then you have to change". Adjusting to taking a large amount of medications at once is difficult for anyone. Marilyn developed adipose fat lumps all over her chest and back as a result of the medicines she was taking. She told me she saw some women who would just never get in line for medications while they were sick. There is a connection here between physical and psychological manifestations of HIV and Carla observed that if women did not have their medications explained to them, they were slow to cooperate in taking them.

Counseling can be a very important process for women who are infected. "Unlike women in other groups, those who have symptomatic HIV infection and AIDS must deal with grief over the loss of their previous body image, sexual freedom, and potential for childbearing" (Zaitzow, 2001: 678) and they have the added worry of dealing with the possible loss of their own lives. Even though Juliette is asymptomatic and has always been, she says she still wants someone to care about her health and ask her how she is. "I still get fatigue, sleepless nights, depression. I want my health valued." As noted in the chapter on stigma, all of the women in my study expressed a need for some type of counseling in order to adjust to having HIV. This is an important step in terms of staying healthy.

For some of the women in my study, learning of their status was nothing compared to dealing with drug addiction. One inmate told me, "I was more worried the drugs would kill me. I can live with this (HIV) but if I kept doing smoking I was gonna die, for sure." These women

needed additional medical attention because of damage to their heart, liver, and blood, but this attention was often not available. There was only one medical unit for the entire population and even though the women lived on the unit, there were always women from population there as well. This meant that the special needs of HIV positive patients could not always be met.

Zaitzow explains that women, in general, require more medical attention than men:

675).

Women often require more medical attention than men, and women's prisons must deal with greater demand for adequate health care. In particular, women experience problems related to their reproductive systems, especially true of those who are pregnant and require prenatal care when they enter prison. A host of other problems related to health care exists in women's prisons, including the availability of specific medications (2001:

Marilyn found out she was pregnant when she was in prison. She spent the first half of her pregnancy on the medical unit. Not only did she require prenatal care, but it was important to her to make sure her baby would be healthy. Historically, policy regarding pregnant inmates has been based around the fact that the offspring is innocent and should receive the best of care. In L. Mara Dodge's social history of the women's prison, he says that pregnant women posed a unique problem because of the financial burden they incurred. Women were also accused of becoming pregnant in order to escape their prison sentence (1999: 915) and numerous arguments about what the official policy would be were never fully articulated. While medical staff may feel an ethical obligation to provide care to a pregnant woman, they may not have a legal obligation to and this is something that differs from state to state. Marilyn was able to go home to have her child because her sentence was almost up. Later, however, she ended up back in prison and being taken away from her child which was, as for many of the mothers I interviewed, a very difficult adjustment.

#### Children

The only time I ever saw Juliette cry was when she talked to me about being separated from her children.

I have learned that it (leaving my children) was because of my addiction and not my natural mind and who I was and my choices of my right mind, but that doesn't make it ok in my soul; that act has already been done. I live with that daily. I don't allow it to control me but you know that never goes away, I will carry that to my grave with me, I will be buried with that grief. And it's almost like what could hurt you? It's like if you have been through the experience of losing your children or losing them through drug addiction, what is HIV? That pain doesn't even touch the fact of what you have done. No pain could be greater for a woman.

Other women in my study echoed her feelings and said the guilt they struggled with on leaving their children was almost too much to bear at times. Tasha added it was also difficult to maintain a relationship with them while you were in prison. She told me that although she wanted to see her children she sometimes felt bad they had to visit her there- "it is prison after all".

The adjustment to new medications and being separated from children was difficult for the women in my study to cope with but, as shown earlier, the women developed different methods of adjusting to prison life depending on their unique biography and identity. Other studies of coping in women's prisons have focused on an almost third wave feminist approach that looks at women as not a homogenous set but as varied depending on many factors (Zingraff and Zingraff, 1980). While this may be helpful in order to shed light on previously neglected needs for the women, Kruttschnitt and Gartner argue that this type of information could be used to strengthen control of women based on perceived risk factors which could affect the level of security she is in, eligibility for parole, and release (2003: 38). The accompanying risk factors associated with HIV/AIDS landed the women in my study in a segregated ward. Although they were more tightly controlled, little attention was paid, at first, to their special needs as HIV positive women. This suggests that by universalizing the experience of an HIV positive female

inmate the prison had, as Kruttscnitt and Gartner argue, "more power to punish some women than others, with consequences for their lives not only in but also after prison" (2003: 44).

### Experiences Beyond the Space of the Prison

A big issue when dealing with inmates, male or female, is recidivism or the return rate. According to the 1999 Bureau of Justice Statistics, the recidivism rate is generally higher for men than for women. It also suggests that because women are incarcerated more often for drug offenses than for anything else that this could account for the lower rate. Drug sentences carry a shorter amount of time than, say, a violent offense, but due to political campaigns such as the War on Drugs, many more first time offenders are being imprisoned than ever before. Becoming trapped in the revolving door of the system is a reality for many women who suffer from addiction or live in poverty. The experience of life on the outside can sometimes be more difficult than the sentence itself.

The rate of return for the women I interviewed was split down the middle with two of the women citing parole violations as the reasons they went back. One woman cycled through for about fifteen years and has been out for one. She told me that drug use and prior offenses contributed to her staying in the system for so long. It was important to all of them to remain on the outside and all of them drew that resolve from a personal feeling of empowerment and agency.

A qualitative study done by O'Brien in 2001 described female inmates released from prison and how they experienced the transition to the outside. These women also described empowerment as the lynchpin in remaining on the outside. Many of the women in my study kept in contact with organizations that would help them post release. Carla and Tasha both volunteered their time at AIDS Inmate Mothers (AIM) after they were released and all of the

women can name at least one group that helped them get set up once they were out. These relationships tied them to a more "normative" lifestyle that helped them stay crime free.

It takes a considerable amount of agency to overcome the obstacles presented to women once they are released. Marilyn said she got off the Greyhound bus with thirty-five dollars to her name. Juliette slept in a shelter in the town her children were in until she was able to get a place to live. The stigma associated with being a former inmate and also being HIV positive, not to mention a woman, is sometimes a frustrating experience. Carla told me she worked two low paying jobs, one as a housekeeper in a hotel and as a cook in a hotel until she was able to get her disability. Marilyn's disability had just come through after five years of back and forth, but she said she still needed to find a job and with her level of health being low it has been difficult.

Although the women in my study have been able to make progress in their lives on the outside, this cannot be said for all women because of the low hand they have been dealt.

Kruttschnitt and Gartner point out that,

The emphasis.... on women's agency as a casual factor in avoiding recidivism needs to be balanced with an awareness of the limited range of choices available to most women released from prison. Seeing agency and empowerment as the most critical factors in reducing recidivism can lead to the conclusion that all that is required to stay crime free is to "just say no", this making women solely responsible for their own success-or lack therof- at avoiding reoffending (2003: 55).

I would add here that even this "agency" can be questioned because they have a limited choice as to how they should live a "normal" life. Fitting into these normative gender roles is exactly what Richie (1996) is describing when she talks about gender entrapment; the idea that the women who find themselves imprisoned all too often do so as a result of trying to fit into social norms for their gender. The pressure they feel to maintain their accepted roles may leave them vulnerable to high risk behaviors such as drug use.

Finally, relationships on the outside contribute to how well a transition can go for the women being released. All Juliette wanted to do when she got out was be near her children. By cultivating a good relationship with DHR while she was in prison, she was able to get her children back once she had settled down. For others, it was not that easy. Marilyn never got her children back from her relative. She said she finally made the choice to let them adopt her daughter after she had been released.

I was kinda hurt in the beginning because she wanted to change her name but now we have a good relationship but every time I go to visit, she doesn't wanna have any time for me but I talk to her on the phone.

Some of the women had difficulty reestablishing a relationship with their children and loved ones. Sometimes the stigma surrounding them as an HIV positive inmate makes family uncomfortable. Juliette described a scene with her daughter after the first time she got out where they were sitting together watching a talk show about a little girl with HIV. Juliette told me her daughter looked up from the television and said,

Mommy, it doesn't make sense for them to treat that little girl like that. I would never judge her because she is HIV but I will tell you one thing, I don't want anybody in my family to have that!

The difficulty in reestablishing a relationship and also having to disclose her HIV status to a young child was "a big bump in the road" for her.

After release from prison, the women in my study often returned to similar economic and social situations they were in before they went to prison. While the programs and organizations affiliated with the prison gave them skills and connections to make better decisions once released, much of what happens will also depend on the women's particular economic background, ethnicity, family situation, etc. While studies focused on pinpointing those particular issues can

be helpful in developing programs and interventions specifically addressing women's needs, there is much to question about the gendered nature of the prison itself and its power to punish.

### A Gender-responsive Prison

As the rate of incarceration increases in the United States, so do the varied responses to control of inmates. Whether it is the new high tech maximum security prisons, or more complex systems of prisoner classification, we see bodies become anonymous numbers in order for the prison to run more efficiently and effectively. When Dodge (1999) traces the history of the female inmate from the nineteenth century on, she describes a prison administration that considers female inmates to be "the worst of the worst" based on the fact that their criminal behavior does not fit accepted gender norms. These roles are the same ones Ritchie (1996) argues trap women and make them susceptible to both abuse and imprisonment.

The prison itself is based on a patriarchal ideology that gives men social control over women's bodies. Efforts to describe the needs of a female inmate inevitably lead to progressive reforms that render the female inmate a "knowable subject" (Carlen, 1983) therefore easier to control. Even so-called feminist prison reforms that call for a gender-responsive prison, or one that is centered on cooperation, agency, and empowerment "still ignore the reality of carceral relations in prison, a reality that cannot sustain a supportive environment" (Krutschnitt and Gartner, 2003: 60). These reforms continue to legitimate the prison as an institution and only justify further expansion of the prison system which supports the "if you build them, we will fill them" attitude of carceral punishment today. The same argument can be made for those living with HIV in the prison system. Through reforms and control that is generally a reflection of hegemonic forces in all of society, state prisons have been able to continue to control and subjugate the HIV/AIDS population so as not to have to deal directly with their individual needs.

While the women in my study would never think of themselves as victims (and I would not either) it is important to stress that although the prison's attempts at control are pervasive, women expressed an incredible amount of agency in dealing with their experiences both inside and outside the walls.

#### 8. CONCLUSION

In this thesis, I have tried to introduce concepts fundamental to understanding the state of the prison system today as well as the social perceptions of those in prison and those who are HIV positive. I wanted to introduce, what many would argue, the outdated practice of segregation of HIV positive inmates and look at how treatment of the women in my study has been uneven and inadequate. I wanted to make the associations between power, knowledge, and isolation in order to show how the prison system legitimates itself even though it can be contradictory.

In addition, I wanted to situate the segregation of HIV positive inmates historically within practices of segregation and confinement of what society deems a "dangerous" person. This highlights society's urge to control and classify people and to establish normative rules for behavior. The literature is varied and plentiful in the ways in which scholars talk about segregation and control and I found those critiques leveled at confinement to be the most relevant to my project.

In researching the women who had been segregated in the medical unit for HIV while they were in prison, I wanted to look at their experiences and constructions of self. I showed that although women struggled at first with acceptance of their stigma, they were able to integrate it with the help of the women around them and by making sense of it themselves through books and literature. I discussed the power dynamics in the prison and how they were constantly negotiated and enforced by the staff and the inmates. I argued that "choice" is a theme that often comes up when dealing with behaviors and in the space of the prison choice is still generally bound up in the system of control. However, the women in my study used a large amount of agency in order to react against a system they believed was unfair and irrational. By forming a

group, they were able to petition for their equal rights and make use of programs and literature to make the most of their time. Finally, I placed them within the context of their gender and argue that their experiences as HIV positive female inmates are not universal, but colored by their own personal histories which all were reflexive about.

### So What about Segregation?

Going into this project, I was curious about the experiences of the women who were segregated, and in the back of my head expected to find a human rights mess. The women did complain about unfair treatment and were glad to get access to the same programs as general population. Yet, they all did not seem to mind being segregated to the degree that I expected. They gave two main reasons for this: the fact that they had to deal with fewer inmates on a day to day basis, and the solidarity they felt with the other HIV positive women.

The first reason, I believe, speaks to the enormous problem of incarceration in this country. With the highest rate of imprisonment in the world, the U.S. has been accused of "warehousing" large numbers of people so as to render them socially invisible. The women on the unit expressed relief in not having to deal with the overcrowding and intensity that was general population. This issue raises an interesting point into the effectiveness of prisons to begin with and the ease with which we lock people away. Perhaps, a better focus would be to reexamine some of the mandatory minimum sentences the Sentencing Reform Act enforced in the early 1980s and give some of the sentencing power back to the judges. In doing this, decisions would be judged on a case by case basis and more emphasis could be put on rehabilitation programs, parole, and number of offenses. This might reduce the number of women going to jail on first time drug offenses and stop targeting minority populations.

The other reason the women gave for the advantages of segregation was the solidarity felt with those who shared their HIV status. This is an important concept when looking at the ways in which the women felt empowered with knowledge. Tasha told me:

There was a bond we felt because of the fact that we were HIV positive. So it was like I am gonna take this from you because I know you are bringing it from your heart. You know what I need. That's so important.

This highlights the need for new players in the field of AIDS policy, education, and empowerment. Policies are generally enacted by larger public health organizations such as the CDC and while they are sound policies, it is sometimes hard to relate them to the world these women live in. What they worry about is whether they will find a job or how they will afford their medicine. Many of those who are powerful enough to make these decisions are not infected or affected. Juliette told me that when she used to sit in on board meetings for various organizations associated with AIDS/HIV prevention and education she was invited as a consumer because many times the grant would dictate that. The issue is minimum community involvement when those who are living with the disease should have much more say. Juliette told me

They can look at you, Emily, and tell you how much they understand and how much they sympathize then when they go on paper and implicate something else service wise, that tells you I don't really understand you nor do I really care. We need more administration that's really committed to this illness. Not to the illness, to saving lives.

Many of the women told me they felt the need to go back to the prison and teach classes after they had been released because they recognized the importance of sharing with someone going through the same things they did. If the focus of these HIV/AIDS programs is sustainability then it seems important to have women who can relate to each other.

The experiences of the women in the prison are remarkable in that they showed such agency and reflexivity in the way they reacted against the system. They also refused to be victimized and made necessary steps in themselves in order to alter their outcomes. Being HIV positive, especially in the Deep South, can be a difficult adjustment, but the women find power in disclosing their status and are proud of the things they accomplished for the prison system. Many of them continue to work with outreach groups and volunteer their time when they are able. While their positions still reflect the disadvantages that exist in the way we control women in both the prison and society, they were thoughtful in the ways in which they fought to subvert the system and its image of femininity. By listening to their experiences we can find important points into which further research and reform can be done.

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